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SIDS-SIBLINGS ON HOME MONITORING:
A DESCRIPTIVE STUDY

by

© SHERRY B. HAYWARD

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

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THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled SIDS-SIBLINGS ON HOME MONITORING: A DESCRIPTIVE STUDY submitted by SHERRY B. HAYWARD in partial fulfilment of the requirements for the degree of MASTER OF NURSING in the Faculty of Nursing.

Phyllis Giovannetti
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Date: May 23, 1985

ABSTRACT

Characteristics of mother-infant interaction were described using The Home Observation for Measurement of the Environment Inventory and The Nursing Child Assessment Feeding Scale with six mother-SIDS sibling dyads on home monitoring. In contrast to 30 normal dyads, mothers of SIDS-siblings were significantly (p=.05) less sensitive to infants' cues during feeding and provided less favorable total stimulation in the home environment. SIDS-siblings were as responsive as infants in the normal group. As more time elapsed since the SIDS death, mothers attributed a larger degree of risk to SIDS-siblings, and dyads exhibited more favorable interactive behaviours, including more reciprocal exchanges and greater maternal involvement with the infant. Mothers of dyads exhibiting more favorable interactions were older with more education, had experienced the SIDS death of a first-born male, had SIDS-siblings who were male and older at the time of data collection and had more positive life circumstances. Factors in which no patterns emerged in relation to mother-SIDS sibling interaction included maternal confidence in the accuracy of monitors, the nature of monitor alarms, and the proximity of anniversary dates to the time of data collection. Mothers' descriptions of their lives underscore the exhausting nature of the concerns and isolation experienced with a SIDS death and care of a SIDS-sibling on home monitoring. Research issues emerged concerning the length of the grieving process and the effect of time elapsed since the SIDS death on maternal perceptions of and involvement with the SIDS-sibling. The presence of the monitor is both a source of comfort and a reminder of the possibility of SIDS.

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TABLE OF CONTENTS

CHAPTER Page

1. Introduction 1
   - Research Questions 6
   - Definitions 7
   - Research Objectives 8
   - Conceptual Model 9
     - Characteristics of the Child Health Assessment Interaction Model 10

2. Review of the Literature 15
   - Elements of Mother-Infant Interaction 15
   - Reciprocity in the Parent-Infant System 16
   - Reciprocal Influences in Mother-Infant Interaction 17
   - The At-Risk Infant and Maternal Responsiveness 18
   - The Influence of the Monitored Infant's Behavior on Parents 20
   - The Influence of Monitor Alarms on Parents 22
   - The Influence of Parent-Infant Interaction and the Home Environment on Developmental Outcomes 25
   - Implications for the Mother-SIDS Sibling Relationship 28
   - The Home Monitoring Experience 30
   - Summary of Literature Review 33

3. Methods 35
   - Design and Analysis 35
   - Sample Selection 37
   - Instrumentation 38

CHAPTER Page

HOME Inventory 39

Nursing Child Assessment Feeding Scale (NCAFS) 44

Measurement of Variables Related to Home Monitoring 49

Procedure 50

Training Procedure 52

Ethical Considerations 53

4. Results 54

Sample Description 54

Study Sample 54

Comparison of Normal and Study Samples 56

Study Results 58

Infant Age and Maternal Attribution of Risk 58

Attribution of Risk and Monitor Alarms 60

Variables Differentiating Dyads in Large and Slight Risk Categories 63

Mother-Infant Interaction and the Home Environment 66

NCAFS and HOME Inventory Scores for Dyads Differing on Demographic Characteristics 82

Maternal Reports About Home Monitoring and Care of the SIDS Sibling 90

Factors Contributing to Maternal Concerns 92

Summary of Results 102

5. Discussion, Conclusions, Limitations Implications and Recommendations 105

Discussion of Results 105

CHAPTER Page

Maternal Attribution of Risk to the SIDS-Sibling 105

Variations Among Mother-SIDS Sibling Dyads on Interaction and The Infant's Home Environment 110

Differences Between the Study and Normal Samples on Interaction and the Infant's Home Environment 117

The Home Monitoring Experience 120

The Conceptual Model 124

Conclusions 126

Limitations 129

Nursing Implications 130

Recommendations 136

REFERENCES 138

APPENDIX I: Nursing Child Assessment Feeding Scale (NCAFS) 147

APPENDIX 2: Home Observation for Measurement of the Environment (HOME) Inventory 150

APPENDIX 3: Guidelines for Descriptive Data About Sample 153

APPENDIX 4: Interview Guide for HOME Inventory 158

APPENDIX 5: Record of Monitor Alarms 163

APPENDIX 6: Consent Form 166

LIST OF TABLES

TABLE Page

1. Characteristics of Study Sample for Each Case 55
2. Frequency Distributions, Means, and Standard Deviations of Demographic Characteristics for Study Sample and Normal Sample 57
3. Maternal Attribution of Infant Risk at Initial and Final Data Collection Visits, Corresponding Infant Age and Age of Previous Baby at SIDS Death, for Each Case 59
4. Maternal Attribution of Infant Risk at Initial and Final Data Collection Visits, Corresponding Confidence in Monitor Accuracy and Frequency of Monitor Alarms, for Each Case 61
5. NCAFS and HOME Inventory Scores According to Maternal Attribution of Infant Risk and Months Elapsed Since the SIDS Death 64
6. Statistical Contrasts on Demographic Variables, Home Monitoring Variables, and NCAFS and HOME Scores for Mothers Attributing Large Versus Slight Infant Risk 65
7. Descriptive Information About the Feeding Observations 67
8. Total and Subscale NCAFS Mean and Standard Deviations for Each Participant 69
9. Total and Subscale HOME Inventory Scores for Each Participant 72
10. Statistical Contrasts Between Study and Normal Samples on HOME Inventory and NCAFS Scores 73
11. Statistical Contrasts on NCAFS Total and Subscale Scores Between Mothers Attributing Large Versus Slight Infant Risk 75
12. Statistical Contrasts on Factored NCAFS Scores Between Mothers Attributing Large Versus Slight Infant Risk 77
13. Statistical Contrasts on HOME Inventory Total and Subscale Scores Between Mothers Attributing Large Versus Slight Infant Risk 78
14. Statistical Contrasts on HOME Inventory and NCAFS Total and Subscale Scores Between the Normal Sample and Mother-SIDS Siblings in the Slight Risk Category 80

TABLE Page

15. Statistical Contrasts on HOME Inventory and NCAFS Total and Subscale Scores Between the Normal Group and Mother-SIDS Siblings in the Large Risk Category 81

16. Demographic Characteristics of Mother-SIDS Sibling Dyads and Matched Mother-Infant Dyads for Each Participant 84

17. Infant Age, Corresponding Risk Category and Ranks on NCAFS and HOME Inventory Scores for Each Participant 86

18. Frequency of Mothers With Concerns About the SIDS-Sibling, Monitor Management and Life Circumstances According to Maternal Attribution of Infant Risk 91

LIST OF FIGURES

FIGURE Page

1. Child-Health Assessment Interaction Model 14

2. Bar Graph of Total NCAFS Scores by Participant and Observation Number 70

CHAPTER 1

Introduction

Advances in medical equipment technology have touched the home as well as the hospital environment. The infant who is on home monitoring requires special kinds of medical considerations, technical equipment and special care. As a result, issues of interest to nurses have emerged, such as those centering on parents who must nurture infants requiring technical care for life-threatening illnesses. There is an element of uncertainty surrounding the infant's physical condition, which in this instance, is the potential for apnea episodes, bradycardia and ultimately cardiac arrest during periods of sleep. Parents of infants on home monitoring face the usual challenges and difficulties of caring for a baby, plus the uncertain occurrence of a medical emergency, the necessity of managing novel, unfamiliar equipment and technical procedures such as cardiopulmonary resuscitation.

The use of cardiorespiratory monitors at home arose from the hypothesis that prolonged apnea during sleep may be one of the final pathways leading to sudden infant death syndrome (SIDS) (Steinschneider, 1976; Valdes-Dapena, 1981). "Prolonged apnea is defined as cessation of breathing for twenty seconds or longer, or as a briefer episode associated with bradycardia, cyanosis or pallor" (American Academy of Pediatrics, 1979, p. 1). The degree of relationship between prolonged apnea and SIDS has not been fully determined. However, in two-thirds of SIDS victims (Kelly & Shannon, 1982), results of tissue studies suggest that death occurs after repeated episodes of hypoxia (hypoventilation) and hypoxemia (decreased oxygen in the blood), probably due to chronic repeated episodes of not breathing adequately (Valdes-Dapena, 1981, p. 6).

About 90 infants per year die of SIDS in Alberta. The rate of death due to SIDS is two per 1000 in the general population. The risk of SIDS increases slightly to 2.1 percent with subsequent siblings (Kelly & Shannon, 1982, p. 1243). As well, 50 percent of infants who experience an unexplained episode of infantile apnea will experience another episode requiring significant intervention to terminate the episode (Kelly & Shannon, 1982, p. 1253). The majority of infants on home monitoring fall into three categories: (a) siblings of SIDS victims, (b) infants who have a history of infantile apnea, (c) and premature infants with recurrent apnea and cyanosis. Home monitoring of these infants is seen to be the means of warning parents about the onset of a potentially fatal episode of apnea and/or bradycardia.

Two home monitoring programs have been established in Alberta, one providing service to families in northern Alberta and the other servicing families living in the southern part of the province. Infants who may be candidates for home monitoring are referred to one of these centers, where physicians, nurses and technical experts are available to provide professional support during the period the monitor is being used. Throughout Alberta, more than 100 infants per year are placed on the home monitoring intervention (J. DeForest, Personal Communication, November, 1983; B. Gumbus, Personal Communication, September, 1983). About one-third of these infants are siblings of infants who have died from sudden infant death syndrome (Mitchell, Personal Communication, April 27, 1984).

The use of monitors at home has been criticized by some physicians because of doubts about the accuracy and reliability of monitors and a concern that the anxiety monitoring may create in parents can result in harmful consequences to family harmony and the parent-infant relationship (Bergman, Beckwith & Ray, 1975; Lewak, 1975; Lucey, 1978; Nelson, 1979). Several researchers have noted that the ease of adaptation to home monitoring and the degree and duration of parents' anxiety seemed to be affected by the frequency and nature of the monitor alarms (Black, Hersher & Steinschneider, 1978; DiMaggio & Sheetz, 1983) and the clinical condition of the infant (Barr, 1980). With the present technical limitations of the machine, monitor alarms are inevitable and often there is no clear explanation as to whether the alarm originated from a machine inaccuracy or an apneic infant. Determining the cause of the monitor alarm rests with the parents' ability to assess their infant's condition and the circumstances surrounding the alarm situation. Southall (1983) notes that monitor alarms, even if most or all are due to machine inaccuracy, may reinforce parents' belief that their baby might die and "result in a self-protective attempt to reduce the pain of impending death, that is, withdrawal of love or even rejection of the child" (p. 133).

In spite of the foregoing expressions of concern, no observational studies have been conducted to determine how home monitoring mediates the parent-infant relationship. What little information has been reported about the parent-infant relationship was based on parents' self-reports about sensitive areas such as the amount of irritation felt towards the monitored infant (Cain, Kelly & Shannon, 1980), whether parents felt they held, played with and enjoyed their babies more or less than average (Black et al., 1978), and how mothers felt about caring for their own babies (DiMaggio & Sheetz, 1983). While parents' attitudes and beliefs are important, this subjective information provides only a small part of the information necessary for determing how the parent-infant relationship is mediated by the use of an apnea monitor.

Relationships are initiated, built, maintained, undermined or terminated on the basis of interactions, or the behaviors that occur between two individuals. To measure only the mother's attitudes and beliefs to the exclusion of behaviors which occur between a mother and infant, is to deny the complexity and essence of the mother-child relationship, that is reciprocity or mutuality. A measure of the mother-infant relationship should include both partners' individual and interdependent contributions to the maintenance of reciprocal interactions. From the infant's point of view, he needs someone who will respond contingently to his signals for interaction. When the infant in turn modifies his behavior in response to his mother's caregiving attempts, then each reinforces the other's behavior. The ultimate goal of reciprocity is mutual enjoyment. When there is mutual enjoyment, parent and infant do not hesitate to return for more such interpersonal moments.

Not only will the reciprocal qualities of interaction facilitate enjoyment between mother and infant, but reciprocity will also foster the infant's development. Part of the mother's role is to provide the infant with the appropriate kind and amount of stimulation. Although some of this stimulation will be available through the richness of the physical environment, the infant still needs a caregiver who can arouse his interest in his surroundings and organize the variety and predictability in his daily life (Barnard, 1983).

Some parents have reported that infants on monitors are held and supervised more than average (Black, Hersher, & Steinschneider, 1978). Because of such reports, it has been suggested by researchers that "monitor usage . . . could induce some developmentally positive changes in the infant's environment and/or social interactions" (Black, Steinschneider, & Sheehe, 1979). The question of the potential of the environment to foster the development of monitored infants is very worthy of study, particularly since there is evidence to suggest that some infantile apnea cases (Korobkin & Guilleminault, 1979) and some infants who suffer from increased respiratory instability in the first week of life may be at risk for developmental delays (Black, Steinschneider, & Sheehe, 1979).

There is minimal information on the effect of home monitoring on aspects of the parent-child relationship. As well, further evidence of the need for research arises from the fact that although the premature infant, SIDS sibling and infant with a history of infantile apnea have characteristics which render them as separate groups, many investigators have studied these groups as a homogeneous population (Black et al., 1978; Cain et al., 1980; DiMaggio & Sheetz, 1983).

Research Questions

This study will examine two questions related to the mother-infant relationship with a group of SIDS siblings who are presently using the home monitoring intervention. These two questions are:

1. What are the characteristics of the home environment, specifically the social, emotional support and cognitive stimulation available to the infant to support his development?
2. What are the reciprocal characteristics of mother-infant interaction during feeding episodes, specifically the mother's sensitivity to infant behavior, response to infant distress, and provision of social-emotional and cognitive growth-fostering experiences and the infant's clarity of behaviors and response to the mother's caregiving?

The home monitoring experience will be considered in terms of how the parent-infant's interaction and the quality of stimulation in the home environment are mediated by maternal reports about the cause of monitor alarms, maternal attribution of risk to the SIDS-sibling, maternal confidence in the accuracy of monitors, and variables concerning the loss of a previous infant from SIDS.

In summary, the purpose of this study is to fill some gaps in our nursing knowledge about mother-infant interaction and the quality of stimulation in the home environment with mothers and SIDS siblings who are using the home monitoring intervention. This knowledge will help to identify nursing interventions aimed at supporting and promoting mutually enjoyable reciprocal parent-infant interactions and growth-fostering home environments.

Definitions

Parent-infant interaction refers to the reciprocal behaviors of a mother and infant during a feeding episode as measured by the Nursing Child Assessment Feeding Scale (NCAFS) (Barnard, 1978a) (see Appendix 1).

The pattern of interaction, as measured by the Nursing Child Assessment Feeding Scales (Barnard, 1978a) refers to sequences of mother-infant behavior which demonstrate the following mother-infant characteristics:

1. Mother is sensitive to infant cues (items 1-16)
2. Mother is responsive to infant distress (items 17-24)
3. Mother provides infant with social-emotional growth fostering experiences (items 28-41)
4. Mother provides infant with cognitive growth fostering experiences (items 42-50)
5. Infant signals the mother with clear cues (items 51-65)
6. Infant is responsive to the mother's caregiving (items 66-76).

The social-emotional support and cognitive stimulation available to the infant in his home environment refers to the mother's emotional and verbal responsivity, avoidance of restriction and punishment, organization of the temporal and physical environment, provision of appropriate play materials, maternal involvement and variety in daily stimulation as measured by the Home Observation for Measurement of the Environment (HOME) Inventory (Caldwell & Snyder, 1978) (see Appendix 2).

Reports about the cause of monitor alarms refers to the frequency with which the mother assigns the source of monitor alarms (see Appendix 5) to the following categories:

1. Infant apnea/bradycardia
2. Equipment difficulty
3. Uncertain (cause could have been due to either the infant or equipment).

Maternal attribution of risk to the SIDS-sibling refers to the mother's statement about the chance (none, slight, moderate, large) of the infant having an episode of apnea or bradycardia (see Appendix 3, question 18).

Maternal confidence in the accuracy of the monitor refers to the mother's statement about degree of confidence (not, slightly, moderately, very confident) that the monitor alarms relay correct information about the infant's respiratory status (see Appendix 3, question 19).

Research Objectives

The objectives of this research study are:

1. Describe patterns between the following variables:
    - 1.1 The risk category in which mothers place the SIDS-sibling.
    - 1.2 Maternal confidence in the accuracy of monitors.
    - 1.3 The hours per day of monitor use.
    - 1.4 The age of the SIDS-sibling.
    - 1.5 The age of the previous infant at the time of the SIDS death.
    - 1.6 The number of months since the SIDS death.

   1.7 Demographic characteristics of the sample.
   1.8 The nature of monitor alarms.
2. Describe patterns of mother-SIDS sibling interaction as measured by the Nursing Child Assessment Feeding Scale (Barnard, 1978a).
3. Describe characteristics of SIDS-siblings' home environments as measured by the Home Observation for Measurement of the Environment Inventory (Caldwell & Bradley, 1984).
4. Describe mother-SIDS sibling interaction and the home environment between mother-SIDS sibling dyads and a normal group of mother-infant dyads.
5. Describe maternal reports about the impact of home monitoring and care of a SIDS-sibling on selected aspects of family life.
6. Describe mother-SIDS sibling interaction and the SIDS-siblings' home environment according to variations in:
   6.1 The risk category SIDS-siblings are placed in by the mother
   6.2 Maternal confidence in the accuracy of monitors
   6.3 The number of months since the SIDS death of the previous infant
   6.4 The number of months the monitor has been used
   6.5 The nature of monitor alarms
   6.6 Demographic characteristics of the sample
   6.7 Maternal reports about the impact of home monitoring and care of the SIDS-sibling on selected aspects of family life.

Conceptual Model

The Child Health Assessment Interaction Model is theoretically sensitive "to the importance of environmental conditions during the first year of life of not only the child but the parents as well" (Barnard, 1978b, p. 18). This model demands that attention be given to the "matrix of circumstances, attitudes, behaviors, affects, perceptions and stimulation that interact to form the quality of the child's environment and to influence the comfort of parents in their role" (Barnard, 1978b, p. 18). Because of the assumption that it is in the interaction of the parent and infant that information about conditions in the ongoing environment will emerge, it is further assumed that microanalysis of parent-infant behavior will provide the most fruitful data.

Characteristics of the Child Health Assessment Interaction Model

Parent and infant are conceptualized as an adaptive interactive system embedded in an environment. Characteristics associated with the infant and the parent as individuals, patterns of parent-infant interaction, and features of the environment have an interactive impact on health and developmental outcomes of the parent and child.

Parents' Beliefs About the Infant

Parents of the young infant are initially learning caregiving and nurturing behaviors that are specifically appropriate to the infant's needs and to cues he gives of those needs (Sander, 1976). To the degree that the infant is predictable and the conditions for learning to care for the infant occur with a minimum of distress and tension, the infant may be easier to understand and get to know. The developing parent-infant relationship may be influenced in a negative way by the acquisition of insufficient or inaccurate information about the infant or by the perception of conditions surrounding the infant as actually or potentially harmful (Kennedy, 1973). The parents of the infant on home monitoring develop a relationship with their infant with learning tasks much more numerous and difficult than the parents of the normal infant. Special knowledge must be acquired to manage the technical aspects of home monitoring. In addition, monitor alarms provide a source of information to parents about the state of their infant's breathing and heart rate from which the parents may form beliefs about the severity of risk to the infant's health and life.

Parents' beliefs and attitudes about their child's health may influence their behaviors in various ways, thus indirectly influencing the child. Parents' beliefs about the severity of risk to the infant on an apnea monitor is a variable of importance in a study of parent-infant interaction with this high-risk group.

The Environment

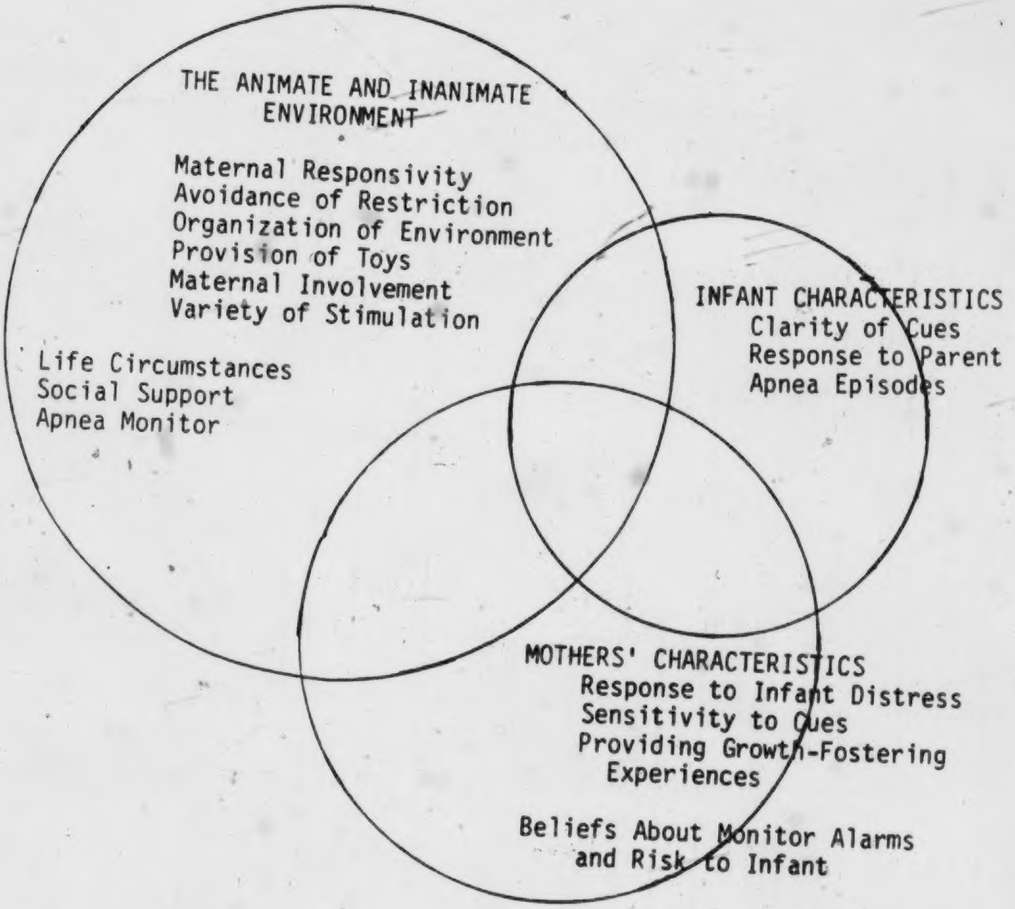
An assumption of this model is that "assessment of the child's environment is important in any child health assessment model" (Barnard, 1978b, p. 7). In this conceptual model, stimulation in the environment is conceptualized as animate, including the experiences of the infant which originate directly from the caregiver and inanimate including the variability and richness of the child's physical world (Barnard & Douglas, 1983). Conditions related to the care of an infant on a monitor, such as mothers' beliefs about the severity of risk to the infant may be reflected in the quantity and quality of stimulation available to the infant in his home.

Mother-Infant Interaction

The purpose of research about relationships is to determine the patterns of interaction between two people. The patterns are theoretical constructs which arise from an aggregation of sequences of interlocking behaviors and the independent behavioral repertoires that make them up. According to Thompson and Walker (1982), "the pattern between one person and another can take many forms, reflecting different conceptual models of relationships and interaction" (p. 890). Therefore, clarification of the conceptual basis of the interaction patterns under study is an essential aspect of research about relationships.

Based on the Child Health Assessment Interaction Model (Barnard, 1978b) the interaction process is conceptualized in terms of basic characteristics of the infant and caregiver that facilitate smooth, synchronous, reciprocal interactions. For the infant, the characteristics are the ability to produce clear behaviors and the ability to respond to the caregiver. For caregivers, the characteristics are the ability to identify and respond contingently to infant behaviors, including distress, and provide the infant with social-emotional and cognitive growth fostering experiences (Barnard, 1978b). These characteristics refer to interactive patterns and could not be the focus of an analysis of individual behavior. For example, the caregiver's sensitivity to infant cues arises from a combination of maternal responses to the specific behaviors of the infant and so is a pattern than cannot be inferred from information about only one participant. From the measurement of independent and interactive behavioral repertoires within the constructs of parent and infant characteristics, patterns of interaction and the relative contribution of each partner to the reciprocal quality of the interaction, can be determined. Figure 1 depicts the interplay of variables between the SIDS sibling, the mother, and the environment. Measurements of mother-infant characteristics that facilitate reciprocal interaction, mother's beliefs about the infant and the environmental stimulation available to support the infant's development provide information which will describe essential aspects of the developing parent-child relationship.

Figure 1. Child-Health Assessment Interaction Model (Adapted from Barnard, NCAST Manual, 1978, p. 18).


THE ANIMATE AND INANIMATE ENVIRONMENT
Maternal Responsivity
Avoidance of Restriction
Organization of Environment
Provision of Toys
Maternal Involvement
Variety of Stimulation
Life Circumstances
Social Support
Apnea Monitor
INFANT CHARACTERISTICS
Clarity of Cues
Response to Parent
Apnea Episodes
MOTHERS' CHARACTERISTICS
Response to Infant Distress
Sensitivity to Cues
Providing Growth-Fostering Experiences
Beliefs About Monitor Alarms and Risk to Infant

CHAPTER 2

Review of the Literature

The purposes of this literature review are to:

1. Clarify the conceptual basis of parent-infant interaction and the effective environment for child development.
2. Identify characteristics of parent-child interaction and the home environment related to positive developmental outcomes for children.
3. Describe aspects of the SIDS-sibling group and the home monitoring experience that may account for variations in measures of parent-infant interaction and dimensions of the home environment.

Elements of Mother-Infant Interaction

Contemporary research on the mother-infant system views the interaction process as a mutually reciprocal dance or dialogue (Bakeman & Brown, 1980; Barnard, 1978b; Brazelton, Koslowski & Main, 1974; Field, 1978). For the interaction to proceed smoothly, the parent and infant must possess a sufficient repertoire of independent behaviors. The infant must be capable of sustaining alertness, hearing, seeing and physical movement. He must have sufficient verbal and nonverbal behaviors to signal a readiness for stimulation or a need for a break or change in the interaction. The mother must be able to present the infant with various amounts and kinds of stimulation through language, touch, movement and facial expressions. She must be able to identify and respond to infant behaviors that signal a readiness for interaction, or delay responding or stimulating until the infant signals a readiness. The mother's tasks also involve communicating information such as affection, approval or disapproval (Barnard, 1983). When the repertoire of behaviors of mother and infant are adequate, then sequences of interactive behaviors with the characteristic of reciprocity are possible.

Reciprocity in the Parent-Infant System

The fundamental and defining characteristic of the interactions making up a relationship is reciprocity, also called pair relatedness, mutuality, or behavioral interdependence (Huston & Robins, 1982), and referred to as reciprocity in this study.

Reciprocity in the parent-infant system involves an exchange of information or stimuli which flows from and relates to previous stimuli. Reciprocity occurs when the response to a behavior is contingent and/or similar in kind to the other's behavior (Field, 1978). Reciprocal behaviors may be child or parent initiated. When the mother presents appropriate stimulation, pauses so the infant can absorb and respond, she is behaving in a reciprocal manner. Similarly, when the mother pauses or slows her activity in response to the infant looking away, falling asleep or fussing, she is behaving contingently to the infant's signals for a break or change in the interaction. Not interrupting, taking turns, respecting the infant's occasional breaks from interaction, and reserving stimulation for periods of attentiveness are features of a reciprocal interaction (Barnard, 1978b; Field, 1978).

The parent and infant will initiate, sustain and terminate interactive sequences in a mutually satisfying way when their behaviors are reciprocal. When reciprocity is lacking the interaction appears less animated, asynchronous and disorganized. The disorganized interaction may be task oriented with little social time or cognitive stimulation, fewer episodes of mutual responsiveness and limited behavioral repertoires of the infant and/or parent. An active, stimulating, intrusive adult and a gaze-averting, unresponsive infant is an example of an interaction lacking in reciprocity and synchrony.

Reciprocal Influences in Mother-Infant Interaction

There is ample evidence in the literature to support the notion of reciprocal influences in the parent-infant system. Behaviors such as vocalizing, smiling and crying are signal aspects of the infant's repertoire, and serve to maintain the proximity and responsiveness of the caregiver. The fact that these behaviors can either elicit responses or occur as a result of others' responses, points to their interactive nature.

Gaze behavior of the infant has been reported to elicit maternal vocalizations and eye contact; whereas, a restricted range of maternal, verbal, or gaze behaviors has been associated with less social behavior from infants (Stern, 1974). Infant smiling has been associated with more maternal responsiveness (Bell, 1971), while increased crying and irritability have been related to less maternal responsiveness (Beckwith, 1972; Bell & Ainsworth, 1972; Campbell, 1979; Cooper & Schraeder, 1982). Robson and Moss (1970) noted that mothers in their study who were classified as late attachers, reported babies who cried more and were late in exhibiting smiling and eye contact.

Research findings on the temporal quality of interactive behaviors, indicate that the ability of mothers to respond contingently to the infants' cues for attention and non-attention, facilitates the smoothness of the interaction (Brazelton et al., 1974; Stern, 1974). Some research findings provide evidence that if an adult's stimulating behavior is not based on the infant's cues for attention and non-attention, the result is increased infant gaze aversion, fretting and less positive affective expression by both mothers and infants (Bakeman & Brown, 1980; Crnic, Ragozin, Greenberg, Robinson, & Bashman, 1983; Field, 1977; Goldberg, 1978).

The At-Risk Infant and Maternal Responsiveness

The question of the high-risk infant's behavior as an elicitor of maternal response was studied by Holaday (1981). The researcher determined that the high-risk infant's crying elicited a quicker response time and closer proximity to the mother, in comparison to the normal group. The researcher suggested that when infants are ill, the nature, severity and consequences of the infant's distress may be less clear to the mother. Thus, she responds quickly to all infant crying, regardless of the context.

Researchers reported increased amounts of maternal involvement and stimulation with infants who were premature (Barnard, 1981; Crnic et al., 1983), or ill (Green, Fox, & Lewis, 1983). Researchers, however, disagree with the outcome of situations where mothers are highly involved with unresponsive or handicapped infants. Barnard (1981b) reported that parents, who initially put out so much effort, showed less sensitivity and responsiveness to their premature infants at eight months of age, suggesting a "super-parent-burn out" phenomenon in parents of children with problems (p. 94). Crnic, Ragozin and associates (1983) reported opposite results, with mothers remaining highly involved with their premature infants throughout the first year of life.

Discrepancies in research results are apparent with reference to the relationships between infant behavioral styles and maternal responsiveness. What appears to be lacking in these studies of mother-infant behavior is a clear, consistent conceptualization of maternal responsiveness. According to Bell (1971), as the tasks of caregiving (e.g., feeding, diapering, relieving distress) increase, the amount of time spent in purely social interaction decreases. So the infant with a more difficult behavioral style or health problem that demands close observation or demands more than usual baby care, may maximize caregiving situations and minimize social interactions.

Bell's (1971) notion of a difference between caretaking and social interactions has been supported by other investigators. Green, Fox and Lewis (1983), in a study designed to determine the independent contributions of prematurity and illness on the infant's behavior and mother's responses, found that sick term and preterm infants were less attentive and fretted and cried more at three months of age than term and preterm healthy infants. Mothers of sick term infants spent the least amount of time in social interaction but the most amount of time in caretaking behaviors, such as relieving distress. These mothers spent more time in proximal and kinesthetic stimulation but demonstrated the least amount of affective stimulation.

Some mothers have behavioral repertoires that are more task oriented and social episodes tend to occur separately from routine care. For other mothers, every interaction is a social occasion. Most studies of mother-infant interaction do not standardize the context of interaction during data collection but sample whatever interactions occur over a specified period of time, regardless of their purpose. Failing to identify the context of interaction reduces the clarity and meaning of the measurements.

The Influence of the Monitored Infant's Behavior on Parents

Caring for an infant who requires a cardiorespiratory monitor results in a set of circumstances that differ from conventional norms. The infant must be either attached to the monitor or constantly observed by his caregiver to ensure his physical safety. As well, parents who have experienced the sudden death of a previous infant may tend to feel somewhat fearful of all young infants (Krein, 1979), may have difficulty getting close to their subsequent infant (Rowe, Clyman, Green, Mikkelson, Haight, & Ataide, 1978) and may have intense self-doubts about their caretaking abilities (McElroy et al., 1979).

Some parents of infants on cardiorespiratory monitors report responding immediately to infant distress and preventing overstimulation for fear that infant fatigue or crying would induce more apnea (Steinschneider, 1974). Mothers were asked to report the amount they held, played with, and enjoyed their babies in comparison to their perceptions of the average time parents spend with these activities. Fifty percent of 31 couples with infants on monitors reported that they held their infants more than average, especially when asleep. One-third reported playing with their baby and enjoying their baby more than average. One-fifth of parents reported holding the child less than average; one-tenth played with the baby less; and one-tenth reported enjoying their babies less than average (Black et al., 1978). The majority of parents perceived the amount of contact with their infant as more than average.

This close contact and proximity of the parent and infant on a monitor sets up circumstances that should facilitate the development of reciprocal mutually enjoyable interactions. Whether this increased contact of the parent and infant actually does result in reciprocal responsivity has never been investigated with the SIDS sibling and parent. Contemporary researchers place emphasis on the reciprocal dimensions of interaction when describing the quality of the mother-infant relationship. It is the quality of mutual responsiveness, not merely proximity, that will facilitate the development of a close relationship between the mother and infant. In the words of Bell (1974):

> the shortcoming of the theory of attachment that Bowlby has developed, is that it does not speak sufficiently to social interactions. . . . Proximity is necessary but not enough (p. 9).

A case study revealing the impact on a mother of her apneic infant's behavior emphasizes the importance of assessing the status of the parent-infant relationship when monitors are used. Prior to the initial apnea episode, the infant's interactive behaviors were within normal limits for a preterm infant. Subsequent to the apnea episode, the infant, for more than three weeks, displayed less alertness and decreased visual and auditory responses. The mother's reports indicated she was acutely aware of the difference in her infant's behavior following the apnea and one hour prior to the apnea episode. When the infant's behavior deteriorated, the mother became anxious, depressed and suffered from fatigue. Two weeks after the mother took the infant home on an apnea monitor, she reported to the nurse: "Since the baby is still on a monitor, I don't feel he completely belongs to me" (McElroy et al., 1979, p. 401).

In summary, there is sufficient evidence in the research literature that infant behavior and parental responses are linked in a reciprocal manner. The focus of this study is on the question of whether parent-infant interaction is mediated by the use of an apnea monitor with a SIDS-sibling.

The Influence of Monitor Alarms on Parents

Authors elaborating on the conceptual elements of interaction note that not only observable behaviors, but also the subjective conditions surrounding the behaviors are relevant elements for measurement (Huston & Robins, 1982; Thompson & Walker, 1982). A subjective condition is an attitude, perception, belief or relatively stable orientation held by the mother about her infant or conditions surrounding the infant. A subjective condition arises out of interaction, and although referred to as stable, may be more or less so, and therefore subject to within person variation (Huston & Robins, 1982, p. 906).

There have been very few studies on how the perceived and actual severity of an illness affects the family or parent-child system. Offord, Cross, Andrews and Aponte (1972) determined that mothers' perceptions of the severity of their child's congenital heart disease, had more effect on family life and the child's adjustment than the actual severity of the disease. Overestimation of severity was greater with lower socioeconomic families and when mothers had lived with an awareness of the child's ill health for some time prior to the formulation of a definite diagnosis by the physician. It seems plausible that anxiety associated with a child's illness may increase the likelihood of parents' overestimating or underestimating the severity of a disease and the risk to the child.

It has been suggested that parents' self-reports about the severity of apnea may not always be accurate due to the high anxiety felt by parents. Nelson (1979) notes that

> the same signs and symptoms in a given apneic infant may lead to resuscitative intervention by volatile parents that would not have produced such a reaction in those more stoic. . . Characterization of these parents . . . could help in the evaluation of this factor and its distribution among several infant groups (p. 8).

The questionable accuracy of parents' perceptions about the occurrence and severity of apnea and bradycardia episodes of infants on home monitors has been commented on by several investigators (Duggy & Bryan, 1982; Kahn & Blum, 1982; Nelson, 1978; Southall, Levitt, Richards, Jones, Long, Farndon, Alexander, & Wilson, 1983).

Although apnea monitors have been made more adaptable for home use, apnea/bradycardia alarms can still be falsely triggered if the leads are incorrectly positioned or the controls on the monitor are not set correctly or need to be readjusted due to a change in the infant's activity level (National SIDS Foundation, 1982). Although a continuous alarm should distinguish an equipment problem from the intermittent alarm of an apnea/bradycardia episode, parents are advised to respond to all alarms as though they might be apnea/bradycardia episodes.

Investigators have made some brief comments with reference to parents' reactions to monitor alarms. Black et al. (1978) said the monitor and alarm rate were parents' best indicator of the severity of risk to their infant. When the rate of monitor alarms diminished or the infants required no stimulation to resume breathing, parents worried less. Barr (1980) reported that parents were generally more anxious if their infant had required CPR. Mothers who reported the experience of caring for their infant in the first few weeks of monitoring as easier than expected, related this ease to few or no alarms or knowing most alarms were false (DiMaggio & Sheetz, 1983).

In the course of responding to the monitor alarm, parents may interpret the cause of the alarm as infant apnea/bradycardia or an equipment problem. In some instances parents may be uncertain if the monitor alarm originated from a "sick infant" or a "sick machine". Although SIDS siblings on monitors are thought to be at greater risk for SIDS, whether or not prolonged apnea or bradycardia will even occur remains an uncertainty. Parents faced with this element of uncertainty may formulate a belief about the severity of risk to their infant, in part, on the basis of their beliefs about the cause of monitor alarms. Equally plausible, are parents who form a belief about the risk to the infant, regardless of the kind of feedback from the monitor.

This study focuses on the question of whether subjective conditions relating to the SIDS-sibling and monitor alarms mediate parent-infant interaction and the stimulating qualities of the home environment. The variables measured in this study include: (a) parent's reports about the cause of monitor alarms and (b) the mother's belief about the degree of risk to her infant of having an episode of apnea or bradycardia. This information will help to infer possible reasons for variations in parent-infant interaction and the home environment as well as provide clues as to why some parents have experienced difficulty terminating infants from monitors.

The Influence of Parent-Infant Interaction and the Home Environment on Developmental Outcomes

A number of investigators have found aspects of caregiver-infant interaction significantly related to later child development. The mutual responsivity of mother and infant and the contingency of maternal responses to such infant behaviors as smiling, vocalizing, and distress have been positively associated with later child performance on tests of mental development (Bakeman & Brown, 1980; Beckwith, Cohen, Kopp, Parmelee, & Marcy, 1971; Cohen & Beckwith, 1979), more secure mother-infant attachments and the infant's ability to cope with stress (Belhar, Lieberman, & Ainworth, 1972; Yarrow & Goodwin, 1965).

The implications of the mother's contingent responsiveness for the infant's cognitive and social development become clear with the recognition that maturational advances depend on the infant's ability to respond to stimulation in the environment. This ability is in turn affected by the degree to which the environment provides opportunities for responding (Escalona, 1968, p. 5). The caregiver's ability to provide the needed doses of stimulation and quiet enables the infant to modulate his state of arousal and attain a level of attentiveness at which he can explore his surroundings and respond to his caregiver (Black, 1976; Donnelly & Conroy, 1979). Stern (1974) suggests, when the infant is helped to regulate his own state of arousal on the basis of an adult's interpersonal behavior, he is acquiring experience with precursors of interpersonal coping and defensive operations.

Researchers who have conducted longitudinal investigations with children who suffered paranatal stress have generally concluded that developmental deficits occurred more frequently with children reared in homes that were growth inhibiting (Caplan, Bibace, & Rabinovitch, 1976; Werner, Simonian, Bierman, & French, 1967; Willerman & Broman, 1970). Certainly, one goal of research concerning children has been to determine the causal links between the caretaking environment and children's later development. Major findings from a longitudinal study of 193 low-risk children from birth to second grade, indicated that a measure of the general quality of the home environment was one of the best predictors of the child's later IQ and language ability (Bee, Barnard, Eyres, Gray, Hammond, Speitz, Synder, & Clark, 1982).

The conceptualization of the child's environment, used in this study and the previously cited research (Bee et al., 1982), originated from the work of Yarrow, Rubenstein, Pederson and Jankowski (1972) and was further developed by Bradley and Caldwell (1976) as the basis for development of a rating scale to measure the growth-fostering potential of the child's environment (Bradley & Caldwell, 1984). Yarrow and his associates (1972) distinguished between the animate and inanimate environment. The inanimate environment refers to the "variety, complexity and responsiveness of objects and stimuli available to the child for exploration and manipulation" (Barnard & Douglas, 1983, p. 88). The animate environment refers to "all experiences encountered by the child which originate with or evolve directly from the caretaker (or other people") (Barnard & Douglas, 1983, p. 89).

Yarrow and his associates (1972) studied the relationship between measures of infant development and dimensions of the environment with 42 infants aged five to six months. The variety of inanimate objects available to the infant correlated more strongly with infant development than the complexity or responsiveness of objects. In terms of the animate environment, the variety and frequency of caretaker stimulation, as well as contingent responses to infant vocalizations were significantly related to measures of infant development and social responsiveness. The researchers also found that dimensions of the animate and inanimate environment were independent of one another in terms of correlation with measures of infant development, suggesting that global assessments of the environment, as depriving or stimulating, may be oversimplified (p. 210).

Maternal responsiveness and involvement with infants and the provision of a variety of age appropriate play materials have been documented by researchers as important contributors to mental development at various stages of early childhood (Bradley & Caldwell, 1976; Elardo, Bradley & Caldwell, 1975; Piper & Ramsey, 1980; Ramey, Mills, Campbell, & O'Brien, 1975). Researchers have also reported the physical and temporal organization of the environment and opportunities for a variety of daily stimulation to be important facets of the environment during infancy (Bradley & Caldwell, 1976; Elardo, Bradley, & Caldwell, 1975). While the older child can initiate some of his activities by himself, the infant is dependent on the caregiver to organize and structure his daily activities. An environment rich in the variety of inanimate objects is of little value to the infant, without the presence of a caregiver who can act as a mediator between the environment and infant.

Implications for the Mother-SIDS Sibling Relationship

There is a technical aspect to mothering the infant on a monitor, not present with a normal infant. The caregiver must remain more consciously aware of the infant's color and breathing and mothers are reported to observe closely the amount of stimulation the infant receives in order to avoid apnea due to fatigue. Out of the 105 parents with other children, 74 (70.5 percent) indicated that the care of the infant on a monitor was more time consuming than the care of previous children (Cain, Kelly & Shannon, 1980). The question arises as to whether the increased demands associated with infant care facilitates or occurs at the expense of social interaction with the infant. As well, there is a question of whether the more technical aspects of infant care promote or interfere with mother-infant responsivity, the mother's sensitivity to her infant's cues for attention and non-attention or the emotional support and cognitive stimulation provided to the infant during familiar caregiving and social transactions.

With respect to the infant on a monitor, reports indicate there may be factors which facilitate and interfere with the quality and quantity of stimulation in the home environment. While parents report more contact with infants, they also report infants have fewer outings and less contact with other people (Steinschneider, 1974). Parents have reported more apnea with both overstimulation and a lack of novel stimulation such as a day with no outings, no visits from other people and no disrupted routines (Black et al., 1978).

Of particular significance is a study reported by Black, Steinschnider, and Sheehe (1979) regarding the relationship between respiratory instability and infant development of 122 full term infants, 28 of whom were being maintained on home monitoring. Those infants classified as having high respiratory instability (based on the frequency and duration of apneic pauses) in the first week of life scored lower than infants with low respiratory instability on tests of psychomotor and mental development at nine months of age. Those infants who continued to have respiratory instability in the fourth week of life, scored particularly low. After equating respiratory instability in the first and fourth weeks of life, infants on monitors scored higher, on the average, in both mental and psychomotor development. However, differences were not statistically significant (p = .20). The authors raise the question of whether or not monitor usage induces some developmentally positive changes in the environment and/or social interaction.

The Home Monitoring Experience

Researchers focusing on the impact of home monitoring on family life report similar patterns of anxiety and sources of stress. In general, parents felt isolated, confined and socially deprived (Black et al., 1978; Cain et al., 1980; DiMaggio & Sheetz, 1983; Wasserman, 1984). In part, these feelings were due to the constant demands of caregiving and inability to find competent and willing babysitters. Parents suffered from fatigue, irritability and depression, particularly in the first few weeks of home monitoring. Black and his associates (1978) reported that 50 percent of parents felt their mental health suffered. Some mothers were anxious, depressed and still on tranquilizers after home monitoring had been terminated.

Marital discord often centered around what was safe care of the infant on a monitor. About 50 percent of parents said their marital relationship improved; while 10 to 14 percent reported a decline in the quality of their marriage. (Black et al., 1978; Cain et al., 1980).

Increased anxiety, tension, and feelings of stress among family members were reported in several studies (Barr, 1980; Black et al., 1978; Cain et al., 1980; DiMaggio & Sheetz, 1983). The pattern reported in all studies indicates that anxiety and tension are greatest in the first week, subside over the next month and generally become minimal following that period. For some the anxiety does not subside (Barr, 1980; Black et al., 1978; Cain et al., 1980).

Mothers reported more anxiety and required more time to adjust than fathers (Black et al., 1978; Cain et al., 1980). In general, mothers felt they carried the majority of the responsibility for home monitoring (Black et al., 1978; Cain et al., 1980; Wasserman, 1984). Black and her associates (1978) reported that more mothers than fathers felt their mental health suffered. Fathers were reported to express less feelings of anxiety but had more concrete concerns about home monitoring such as the potential for monitor failures (Cain et al., 1980). Fathers were inclined to estimate higher false alarm rates than mothers and were more skeptical about the potential for SIDS and the positive aspects of using the monitor (Black et al., 1978).

Generally, previous research data indicates that home monitoring was more of a burden for mothers than for fathers. Although the focus of this study is on mothers and their SIDS siblings, this focus was used to reduce the complexity of the study and in no way negates the importance of the father-infant relationship. Because researchers report differences between mothers and fathers in the nature of the concerns experienced with home monitoring, then the father-SIDS sibling relationship would seem to be an area worthy of a separate research study.

According to reports, parents were also plagued with difficulties concerning the monitor, including mechanical failures, many false alarms and difficulty hearing alarms. Since these reports, monitors have been made more adaptable for home use, possibly lightening the load associated with the care of the infant.

Families who have lost a child due to sudden infant death syndrome have a higher incidence of adjustment problems and are at risk for psycho-social difficulties (McElroy et al., 1979). Based on a questionnaire data provided by 32 parents of SIDS victims, DeFrain and Ernst (1978) reported that the death of the infant was rated as the most severe crisis experienced. On the average it took parents 15.9 months to regain their previous level of personal happiness and 8.2 months to regain their former level of family organization.

A report by Mandell and Wolfe (1975) on the unusually high incidence of spontaneous abortion and infertility in 32 women whose children died of SIDS, emphasizes the importance of completing the mourning process prior to having another child. Reports indicate if grieving can take its normal course, the psychological environment for the subsequent newborn maybe healthier (Poznanski, 1972; Rowe, Clyman, Green, Mikkelsen, Haight, & Ataide, 1978). This evidence suggests that measures of parent-infant interaction and the home environment may be mediated by the amount of time between the SIDS death of the previous infant and the birth of the infant who is now on home monitoring.

The number and ages of other children in the family may also be a significant intervening variable in parental adjustment. For parents who have experienced the death of an infant, whether their experience as parents included the care of a child who survived or only the care of an infant who has died may affect their confidence about their abilities as caregivers.

Grief reactions may surface again on anniversary dates (e.g., the date the baby died; the birthday of the deceased infant; the date on which the subsequent infant reaches the age at which the previous infant died; or holiday seasons). These times remind parents of their loss and force them to face the pain again (Krein, 1979; Poznanski, 1972). Should these low points occur at the time of data collection, it may affect results.

In summary, factors relating to the home monitoring experience and the death of a previous infant from SIDS, may account for some sources of variation in measures of parent-infant interaction and dimensions of the home environment.

These factors include:

1. The number of months between the death of the previous infant from SIDS and the birth of the monitored infant.
2. Anniversary dates associated with the SIDS death.
3. The number of months the family has used the cardiorespiratory monitor.
4. The number of older surviving children.
5. Technical limitations of cardiorespiratory monitors.

Summary of Literature Review

The following ideas emerged from the review of the literature:

1. The reciprocal qualities of parent-infant interaction, specifically, mutual responsivity and the contingency of parental responses to infant cues influence the child's later developmental capabilities and facilitate the maintenance of a close mother-child relationship.

2. When infants require more than the usual amount of baby care due to a difficult behavioral style or health concern, caretaking may occur at the expense of social interaction.
3. The quality and quantity of stimulation in the home environment has a mediating influence on developmental outcomes for children.
4. Parents who have lost a child due to SIDS face a number of challenges and difficulties with the care of a subsequent infant on an apnea monitor including: (a) dealing with unresolved or recurring episodes of grief; (b) maintaining hope for the monitored infant's survival in the face of monitor alarms whether false alarms or due to apnea; and (c) developing a mutually enjoyable relationship with the infant while managing the technical aspects of home monitoring. The focus of this research is on the mediating influence of home monitoring, monitor alarms, and maternal beliefs about the severity of risk to the infant on mother-infant interaction and the quality of stimulation in the home environment.

CHAPTER 3

Methods

The objective of this study is to describe the characteristics of mother-infant interaction with mother-SIDS sibling dyads using the home monitoring intervention. The methods used in this study including the design and analysis, sample selection, instrumentation, procedures and ethical considerations are outlined in this section.

Design and Analysis

The design of this study was descriptive. The characteristics of mother-infant interaction and the social, emotional and cognitive support available to the child in his home environment were measured. As well, a variety of information was collected by interview on variables related to the home monitoring experience, the loss of a previous infant, and maternal perceptions of the infant on home monitoring. These measurements included:

1. The number of hours per day of monitor use over seven days.
2. Maternal beliefs about the degree of risk to the SIDS sibling.
3. Maternal confidence in the accuracy of monitor alarms.
4. The frequency and type of monitor alarms.
5. The age of the previous infant at the time of the SIDS death.
6. The sex of the previous SIDS baby.
7. The number of months since the occurrence of the SIDS death.
8. The number of months between the SIDS death and the birth of the subsequent infant.

9. The number of months the cardiorespiratory monitor has been used.
10. Life circumstances including: financial status; employment status; social support; perceptions of aspects of home monitoring; loss of an infant and care of the subsequent infant.

Student's t tests were used to determine if significant differences on demographic variables existed between the study sample of six mother-SIDS siblings and the normal samples of 30 mother-infant pairs. The Mann-Whitney U Test was used to determine if significant differences existed between the study and normal sample on home environment and mother-infant interaction data. The Mann-Whitney U Test was also used to determine if significant differences between mothers who attributed large versus slight risk to their infants existed on home monitoring variables, mother-infant interaction, and the home environment. The objective was to determine factors which might influence variations in interaction and the home environment with the six mothers and their SIDS siblings.

Although measurement in this study produced ratio data, a non-parametric distribution-free statistical test was determined as most suitable for this sample size of six. The Mann-Whitney U Test is a non-parametric statistic which is used as an alternative to the parametric t test when the assumptions of the t test have not been met. The Mann-Whitney U Test analyzes the separation between a set of sample scores and determines the probability of getting the obtained separation or even greater separation if both sets of scores are random samples from an identical population. The larger the separation between two sets of scores, the more reasonable it is that they are not random samples from the same population. The more overlap there is between two sets of scores the more reasonable it is to assume that differences in scores are due to chance (Pagano, 1981; Siegel, 1956).

Statistical analyses were done to determine what, if any, demographic variables may have influenced differences on NCAFS and HOME Inventory scores between dyads in the large and slight risk categories. The direction and significance of NCAFS and HOME differences based on demographic variables were compared across the following three groups: (a) Six mother-SIDS sibling dyads; (b) The 30 normal mother-infant dyads from the general population; (c) Six mother-infant dyads matched to the six mother-SIDS siblings on several demographic variables.

Statistical contrasts were calculated using a two-tailed student's t test for independent groups with separate variances for the normal group and the Mann-Whitney U test, one-tained for small sample sizes for the SIDS-sibling and matched dyads. Differences on subscale scores that were significant and in the same direction in at least two of the three groups, including the normal sample, were considered more likely influenced by the corresponding demographic characteristic.

Sample Selection

The sample of mother-SIDS sibling dyads was chosen through the Infant Home Monitoring Program servicing Northern Alberta. Any family in the Edmonton area with a SIDS sibling less than 12 months of age who was presently or had used a cardiorespiratory monitor at home was considered for selection. Six mother-infant dyads in Edmonton were contacted by the nurse of the Home Monitoring Program and all signed an informed consent to participate in the study. Two families were not contacted, one because of family illness and one because the infant was living in a foster home. Eight mother-SIDS sibling dyads living in rural Alberta were not contacted because travelling distance rendered their participation in the study impractical for the researcher.

The six mothers who agreed to participate in the study were contacted by phone and a time and a date were established for the first home visit. Data collection began after mothers had signed an informed consent.

For comparison purposes, a normal group of 30 mother-infant dyads was selected from a large sample of data gathered by the University of Washington on infants in Calgary and Edmonton. Data for these 30 dyads were available on demographic characteristics, mother-infant interaction using the NCAF Scale, and the quality of the home environment using the HOME Inventory. The 30 mother-infant dyads were selected so that demographic characteristics including infant age, maternal age, marital status, race and number of older children matched the six mother-SIDS sibling dyads as closely as possible.

Instrumentation

The Nursing Child Assessment Feeding Scale (Barnard, 1978) and the Home Observation for Measurement of the Environment Inventory (Caldwell & Bradley, 1984) were the main measuring instruments in this study. As well, two questions and a form for self recording of monitor alarms were developed to measure variables related to the home monitoring experience with a SIDS sibling.

HOME Inventory

The following areas will be discussed with reference to the Home Observation for Measurement of the Environment (HOME) Inventory: Purpose, selection of test items, format, scoring procedure, reliability, and validity.

Purpose

In 1968 a group of researchers began a study of the young child's environment to determine the features of the home most likely to influence development (Elardo, Bardley & Caldwell, 1975). From this initial research, the HOME Inventory was developed as a measure to determine if the child was at risk for developmental failure prior to the age of three years. The HOME Inventory is a measure of the cognitive, social and emotional support available to the child in his home environment. Parental involvement and responsivity as well as inanimate features of the environment are measured. Psychometric testing of the tool has supported the HOME Inventory as a more sensitive measure of the growth fostering potential of the child's environment then a socioeconomic label or developmental test alone (Caldwell & Bradley, 1984).

Selection of Test Items

The original tool, known as The Inventory of Home Stimulation, consisted of 72 observational items. The current version is the fourth revision of the tool and consists of 45 items. Two-thirds of the items are observational and one-third require parental report (Caldwell &

Bradley, 1984). Six conceptual categories were determined by a factor analysis, specifically a varimax rotation with an eigenvalue cut off of 1.0. Items are arranged so that the first item on each subscale has the highest loading on that factor (Caldwell & Bardley, 1984).

Correlations of each item with the subscale and total score and a coefficient of items' difficulty and discrimination level were computed to determine which items should be retained. Point biserial correlations were greater than .25 for items retained. From 30 to 80 percent of subjects were recorded as getting credit for the majority of 45 items (Caldwell & Bradley, 1984, pp. 20-27).

Format

The present version of the HOME Inventory is made up of 45 binary "yes/no" items divided into six subscales: I. Emotional and Verbal Responsivity of the Mother; II. Avoidance of Restriction and Punishment; III. Organization of the Environment; IV. Provision of Appropriate Play Materials; V. Maternal Involvement; and VI. Opportunities for Variety in Daily Stimulation (see Appendix 2).

Scoring Procedure

Each item is scored as a yes or no. Subscores and the total score are determined by the number of yes responses. Higher scores indicate more favorable home environments.

Reliability

The reliability measures were determined from a sample of 174 families living in Arkansas. Children ranged in age from birth to three years. The internal consistency (Kuder-Richardson reliability coefficients) was .89 for the Total HOME Score and for the subscales were .72 (Emotional and Verbal Responsivity of the Mother), .67 (Avoidance of Restriction and Punishment), .89 (Organization of the Environment), .77 (Provision of Appropriate Play Materials), .69 (Maternal Involvement), and .44 (Variety in Daily Stimulation) (Caldwell & Bradley, 1984, p. 19).

The stability of the HOME data from 91 families collected when the child was six, twelve and twenty-four months was determined to be moderate to high with coefficients ranging from .24 to .77. The mean total score was reported to increase over two points between six and twelve and twelve and twenty-four months (Caldwell & Bardley, 1984). These measures indicate that HOME Inventory scores tend to be higher for older children. One reason is due to the provision of different types of toys after the child becomes more mobile and coordinated (Caldwell & Bardley, 1984). No short term test-retest reliability has been reported for the HOME Inventory.

Validity

Bradley, Caldwell and Elardo (1977), investigated the concurrent validity of the HOME Inventory and determined that low to moderate significant correlations (p=.05) existed between HOME Scores on all subscales and socioeconomic status variables. Variables included: Mother education (.22 - .51), father presence (.22 - .40), father education (.28 - .57), father occupation (.24 - .54) and a crowding ratio (.21 - .48). Mother occupation was the only variable that did not correlate significantly with any subscale.

Several researchers have demonstrated a relationship between the child's early environment as measured by the HOME Inventory and other constructs such as malnutrition, language ability, school competency and cognitive development. A study by Cravioto and Delicardie (cited by Caldwell & Bradley, 1984) demonstrated that children at six and forty-eight months who were severely malnourished obtained significantly lower HOME scores (.32) than a group of matched controls.

Elardo, Bradley, and Caldwell (1977) found significant correlations (p=.05) between six month HOME scores on Maternal Involvement (.38), Provision of Appropriate Play Materials (.33) and the Total HOME score (.38) and language development at 37 months. Significant correlations (p=.01) ranging from .46 to .66 were found between HOME subscales at 24 months and language development at 37 months. Wulbert, Inglis, Kriegsman, and Mills (1974) also found a significant difference (p=.001) on HOME scores for a language delayed and a normal group. HOME data on 286 children at 12 months of age were reported to predict elementary school competence with a 22 percent error rate (VanDoorninck, cited in Caldwell & Bradley, 1984). This error rate was lower than the error rate obtained using social class as a predictor.

Several studies have been done to determine the validity of HOME data for predicting mental development. The significance of correlations increased as the child's age increased. On a longitudinal study of 77 families, correlations between HOME data at six months and the 12 month Bayley Mental Development scores were significant (p=.05) for only two subscales. However, significant correlations (p=.05) between six month HOME data and 36 month Stanford Binet scores were found on all subscales with coefficients ranging from .24 on Avoidance of Restriction to .50 for the Total HOME score (Elardo, Bradley, &

Caldwell, 1975). HOME data at six months were significantly correlated on four subscales with 54 month Stanford Binet scores. Significant coefficients ranged from .28 (p=.05) for Maternal Involvement to .44 (p=.01) for the Total HOME score (Bradley & Caldwell, 1976).

The older the child when HOME data were collected, the more subscales there were that correlated significantly with mental development and the stronger were the correlations. All correlations between HOME data at 24 months and 36 month Stanford Binet scores were significant with coefficients ranging from .41 (p=.01) to .70 (p=.01) (Elardo, Bradley, & Caldwell, 1975). Twenty-four month HOME data and 54 month Stanford Binet scores were significantly correlated on all subscales. Coefficients ranged from .28 (p=.05) to .56 (p=.01) for subscale scores with a coefficient of .57 for the total score (Bradley & Caldwell, 1976).

Studies done by other researchers also attest to the usefulness of the HOME Inventory for predicting cognitive failure. Frankenburg and associates (as cited in Caldwell & Bardley, 1984), using a discriminant analysis made up of HOME subscales, from data on 91 children at six months of age, correctly identified 71 percent of these children at 3 years with an IQ of 70 or less. Sixty-two percent with IQ's of 90 or above were identified correctly (Caldwell & Bardley, 1984).

In summary, researchers have demonstrated that significant relationships exist between HOME Inventory measurements and children's physical health and mental development. The HOME instrument was sensitive to severely malnourished children as well as those with failures in cognitive and language development. On the basis of longitudinal studies researchers reported greater predictability of cognitive development when the child was 36 and 54 months (R=.54 and .50) than 12 months (R=.30) from HOME data collected at 6 months of age. The moderate correlations between HOME data and socioeconomic status indicators and cognitive development measures, support the HOME Inventory as a more sensitive measure of the growth fostering potential of the child's environment than a socioeconomic label or performance on standardized tests. In terms of construct validity, the HOME Inventory contributes some unique information about the child's environment while still touching on dimensions that would also be found using socioeconomic status or developmental measures (Bohrnstedt, 1970, p. 95; Campbell & Fiske, 1970, p. 117).

Nursing Child Assessment Feeding Scale (NCAFS)

The following areas will be discussed with reference to the NCAFS instrument: Purpose, format, scoring, reliability and validity.

Purpose

A longitudinal nursing study of 192 families was initiated in the 1970's to determine what early factors are predictive of later child development and health status (Bee, et al., 1982). The families were followed from the time the mother was in her last trimester of pregnancy with her first child until the child was in grade two. A broad range of variables were used to measure perinatal status and health during infancy, the child's performance on standardized tests, mental, language and interpersonal skills, the ecological characteristics of the family, the mother's perception of the infant, parent-infant interaction and the general quality of the home environment. Early results, (Barnard & Eyres, 1979) indicated the mutuality of mother and infant behaviors was critical at every age of infant assessment. From a factor analysis of infant and maternal behavior, emerged conceptual categories and items that measured concurrent mother-infant behavior during feeding and teaching episodes (Barnard & Eyres, 1979). From over 300 single items, the present format for the teaching scale is 73 items and for the feeding scale, 76 items. The original format for the scales involved five to seven point ratings for each item. The difficulty of training and obtaining high interrater agreement led to revisions and the present binary, "yes/no" format (Barnard, 1983).

The NCAF Scale is used to measure the characteristic of reciprocity or mutuality of parent-infant behavior during feeding interactions. The main constructs are sensitivity and responsiveness of each member of the dyad. The parent scales also measure the affection, approval and information about the environment communicated to the infant during the interaction.

Format

The NCAFS instrument is made up of 76 "yes/no" items organized into six conceptual categories. Four categories describe the adult's behavior, including: Sensitivity to Infant Cues, Response to Infant Distress, Social-Emotional Growth Fostering and Cognitive Growth Fostering Activities. Two categories describe the infant's behavior, including: Clarity of Cues and Responsiveness to the Parent (see Appendix 1).

Scoring Procedure

Each item is scored as a yes or no. Subscale and total scores are determined by totalling the number of yes responses. Summing the yes responses for subscales measuring parent behavior and child behavior will give a total parent and total child score. Higher scores indicate more favorable interactions.

Reliability

Reliability measures were determined from a sample of 400 parent-infant dyads from birth to 12 months living in the Western United States. Cronbach's alpha reliability estimates for the subscales were .60 (Sensitivity to Cues), .69 (Response to Distress), .63 (Social-Emotional Growth Fostering), .69 (Cognitive Growth Fostering), .56 (Clarity of Infant Cues) and .58 (Responsiveness to Parent). The reliability for the Total Parent score (subscales I-IV) was .83 and for the Total Child Score (subscale V-VI) was .73 (Bee, 1981). These coefficients indicate the total parent and child scores are more reliable measures than subscale scores. Parent subscores are more reliable than child subscores.

The results of internal consistency measures on the NCAF scale were also reported from the scores of 185 dyads living in Seattle, Washington, in a study comparing the effectiveness of three Newborn Nursing Intervention Models (Barnard, Booth, Mitchell, & Telzrow, 1982). Cronbach's alpha co-efficients on scores obtained at 3 and 10 months of age, respectively, were as follows: .74 and .71 (Sensitivity to Cues); .90 and .88 (Response to Distress); .77 and .81 (Social-Emotional Growth Fostering); .69 and .79 (Cognitive Growth

Fostering); .78 and .70 (Clarity of Cues); .76 and .70 (Response to Parent); .91 and .90 (Total Parent Score); .86 and .82 (Total Child Score); and .94 and .91 (Total NCAFS Score).

There has been no short term test-retest reliability reported for the NCAF Scale. A generalizability coefficient reflecting the stability of scores for 30 subjects at one, four, eight, and twelve month observations was .75 for the Total Parent score and .51 for the Total Child score. Because these measurements are so far apart it is difficult to determine to what degree they reflect developmental change or unreliable scales.

Validity

There are two sources of concurrent validity of the NCAF Scale. Significant correlations were found between HOME Inventory and NCAF Scale scores. The coefficients were significant for all NCAF subscales (p=.01), but Emotional and Cognitive Growth Fostering subscales were the most strongly correlated to the Total HOME Inventory score (.47 and .50). The correlation coefficient for the Total Parent score was .48.

Significant correlations (p=.01) were found between the Nursing Child Assessment Teaching Scale and the NCAF Scale on subscores and total Scores. The highest coefficients occurred with the Cognitive Growth Fostering (.41) and Total Parent scores (.47). These coefficients indicate a moderate relationship between parent-infant interaction scores in two separate contexts, teaching and feeding.

Three separate studies including Barnard's on premature infants, Lobo's on failure-to-thrive infants, and a study by Barkauskas on low education mothers (as cited in Bee, 1981), provide evidence that the

NCAFS is sensitive to mother-infant dyads with special problems. When there was an infant problem such as prematurity, the child score was low (14.3 versus 20.7 for normals); where there was a parent concern such as low education, the parent score was low (34.8 versus 41.9 for normals); and where mother and infant were expected to be part of the problem, as in failure-to-thrive situations, both the child score (16.2 versus 20.7 for normals) and the parent scores (35.2 versus 41.9 for normals) were low.

A factor analysis of the NCAF Scale using data from infants one to twelve months of age, identified eight factors using 53 of the original 76 behaviors (Bee, 1981). Four of the eight factors included both parent and child behaviors indicating the tool is tapping aspects of contingent responding or mutuality. The eight empirical factors did not match the original six conceptual groupings. Because there is no unique solution for a factor analysis, this lack of match does not indicate the conceptual groupings are wrong, but rather, that there are different theoretical ways of looking at mother-infant interaction. However, the empirical clusters with items based on factor loadings probably have a higher internal consistency and so may be a useful and more reliable alternative for scoring mother-infant interaction (Bee, 1981).

Information on predictive validity is limited. On a sample of 30 dyads, regression analysis was used to predict development from NCAF Scale scores. Multiple R's were in the range of .40 to .60 but none reached statistical significance (Bee, 1981). Because the sample was small and homogeneous with reference to demographic features and normal infant development, the researchers felt optimistic about these results. No other predictive studies using the NCAF Scale have been reported.

Measurement of Variables Related to Home Monitoring

The type and frequency of monitor alarms were determined by mothers' self recordings over a month on a form specifically designed for this study (see Appendix 5). Apnea/Bradycardia alarms that were recorded on this form were corroborated by checking the record of monitor alarms kept by parents for the staff of the Home Monitoring Program.

A measure of the mothers' attitudes about the accuracy of monitor alarms was determined by their responses to the following question: "Which category best describes how confident you are that the monitor is accurate?"

1. Not confident about the accuracy of the monitor.
2. Slightly confident about the accuracy of the monitor.
3. Moderately confident about the accuracy of the monitor.
4. Very confident about the accuracy of the monitor.

Accuracy referred to the mother's belief that monitor alarms give correct information about the status of the infant.

A maternal belief about the severity of risk to the infant was measured by the mother's rating on the following question: "Which category best describes your feelings about the chance of your infant having an episode of apnea?"

1. No chance

2. Slight chance
3. Moderate chance
4. Large chance

Questions pertaining to infant risk and monitor accuracy were asked during initial and final data collection visits in order to determine the stability of the mother's responses over a one month period. In the case of two mothers who had discontinued the monitor, this information was collected from a retrospective point of view when the infant was two to four months of age. These questions were developed specifically for this study and no measure of their reliability or validity has been determined.

Procedure

All participants were observed and interviewed in their own homes. Mothers were prepared for the data collection period by a brief warm-up discussion followed by an explanation of what would take place during home visits. Mother-infant interaction during a bottle or solid feeding was observed with each participant on two separate occassions. The entire feeding was observed. The presence of other people such as older siblings, was permitted as long as the situation represented a typical feeding. Mothers were given the following instructions about the feeding observations:

> So I can learn more about how your baby behaves, I would like to watch you feed him/her. Just feed him/her as if I weren't here. If the phone rings or other events occur, just carry on as you normally would. I won't talk to you during this time, because I don't want to interfere with what usually happens. You can tell me when you are ready to begin and

> when you are finished. When you are done I will take a few notes.

An observation-interview of about one hour was done which focused on the child's environment. Visits were arranged when the infant was awake and could be present with the mother. The interview began with an open-ended question about the mother and infant's typical day and followed with probing questions where more detail was needed (see Appendix 4). Mothers were given the following information about the home interview:

> The purpose of the interview is to learn about how your child is, in his own environment; his routines during the day, the things he does, the things you do together in and outside of the house and your observations about how he is growing and developing. The interview will take one hour and needs to occur when you and your baby are feeling good and when your baby is awake and can be present. I will be taking some notes while we talk to make sure I haven't forgotten anything.

A structured interview was used to obtain information about maternal perceptions of infant risk, maternal confidence in the accuracy of the monitor, and descriptive information on demographic and family background variables (see Appendix 3). Data were collected on the apnea/bradycardia episodes that the mother recorded prior to data collection. The apnea monitor had been discontinued by two participants. Four participants with infants presently using the apnea monitor were asked to keep a record of all monitor alarms including loose lead alarms and the reason these alarms occurred, for a one month period (see Appendix 5).

During the course of the interviews and observations, information concerning the experience of losing an infant due to SIDS and caring for a subsequent infant on an apnea monitor was documented. The information participants offered was documented during the visit and checked with other individuals in the sample to help determine common and unique experiences and feelings among six families.

The series of four data collection visits included: (a) an introductory interview to explain the study and collect data pertaining to family background and demographic information; (b) two feeding observations, and (c) an observation-interview pertaining to the home environment. Data collection visits occurred one week apart and each visit lasted from 1 to 2 hours. Each observation-interview included a discussion about the home monitoring experience. The order of the interviews and feeding observations varied according to the infant's readiness for feeding.

Data collection occurred only with mothers and children. This approach was used to reduce the complexity of the study and in no way negates the importance of fathers and significant others.

Training Procedure

The investigator was certified to use the HOME Inventory and NCAF Scale through the Nursing Child Assessment Satellite Training (NCAST) Program offered through the University of Washington, Seattle. Training was reviewed immediately prior to data collection and interrater reliability was established using the following procedure: Two raters observed six interactions using the NCAF Scale and did ten interviews using the HOME Inventory. Following each interaction and home interview, the raters scored the research instruments independently of one another. Interrater reliability was established on the basis of the percentage of items that both raters observed and agreed on. The interrater agreement on the HOME Inventory for ten visits ranged from 91 percent to 100 percent with an average of 96.7 percent. The interrater agreement on the NCAF Scale for six visits ranged from 91 percent to 97 percent with an average of 93.2 percent.

The percentage of agreement approach expresses reliability as the number of times the raters agree relative to the total number of observations made. This is the method of choice when data are categorical, as with these binary, "yes/no" scales (Goodwin & Prescott, 1981, pp. 325-329).

Ethical Considerations

All participants were given an explanation of the study and their role. Participants signed an informed consent (see Appendix 6) and were advised of the following rights:

1. Their participation is voluntary and they may withdraw at any time.
2. They may refuse to answer any question.
3. All information will be held in confidence.
4. Data results will be reported in a manner that does not disclose the identity of any subject.
5. Participants may not find any personal benefit from participating in the study.
6. All notes or forms identifying the participant by name will be destroyed upon completion of the written research report.

CHAPTER 4

Results

The objective of this study is to describe the characteristics of mother-infant interaction with mother-SIDS sibling dyads using the home monitoring intervention. In this chapter, the findings from the NCAFS, HOME Inventory and measurements pertaining to the characteristics of the sample and home monitoring experience are presented.

Sample Description

Demographic characteristics of the mother-SIDS sibling sample and a normal sample of mother-infant dyads were ascertained. Comparisons were made to determine differences between the two groups on demographic variables.

Study Sample

Six mother-SIDS sibling dyads participated in the study. All mothers had lost an infant due to SIDS, anywhere from 13 to 35 months previously. SIDS-siblings were between one and 11 months of age. Four SIDS-siblings were still using the monitor during the data collection period while two had discontinued the monitor two and four months previously. All mothers began monitor use within one to two weeks following the infant's birth. Three of the six infants were male and three were female. Five of the SIDS-siblings were the same sex as the previous SIDS baby. All mothers were married.

Table 1

Characteristics of Study Sample for Each Case.

Maternal Age[a]	Maternal Education[b]	Employment of Spouse	Yearly Income	Older Children	Infant Age[c]	Infant Sex
22	11	Unemployed	19,000	0	7[d]	Female
24	13	Employed	36,000	1	2	Female
24	12	Employed	29,000	0	11[e]	Male
23	11	Unemployed	11,000	1	3	Female
29	13	Employed	36,000	1	1[f]	Male
33	15	Employed	30,000	0	4	Male

Note. N=6 cases in study sample.

[a] Maternal age given in years at birth of infant.
[b] Maternal education given in years.
[c] Infant age given in months.
[d] Apnea monitor discontinued at 5 months of age.
[e] Apnea monitor discontinued at 7 months of age.
[f] Second SIDS-sibling on apnea monitor.

Table 1 presents the following demographic information for each of the six participants: Maternal age at the birth of the infant, maternal education in years, employment status of spouse, yearly family income, number of older children, infant age in months and sex of the infant. Mothers ranged in age from 22 to 33 years with 11 to 15 years of education. Three families had older children and three did not. One infant was a second SIDS-sibling on an apnea monitor. Two spouses were unemployed at the time of data collection and family incomes ranged from $11,000 to $36,000 per year.

Comparison of Normal and Study Samples

Sixty percent of the sample of 30 mother-infant dyads were from Edmonton and 40 percent were from Calgary. Table 2 compares the frequency distributions, means and standard deviations of the study and normal samples on the following demographic characteristics: Infant age in months; maternal education in years at the birth of the infant, the number of older children in the family, sex of the infant, marital status, race, city of data collection and type of feeding for the interaction observation. Percentage frequencies for infant sex, marital status and race were closely matched between the two groups. Because ranges and variances on demographic variables were similar for the two samples, a student's t test for independent groups was done to determine if significant differences (p .05, two-tailed) existed on demographic characteristics. As expected with matched samples, no significant differences were obtained between the samples on the variables measured, including: maternal age at the birth of the infant

Table 2

Frequency Distributions, Means, and Standard Deviations of Demographic Characteristics for Study Sample and Normal Sample.

Demographic Characteristic	Study Sample[a] Frequency	Normal Sample[b] Frequency	Study Sample		Normal Sample	
			Mean	SD	Mean	SD
Infant Age (in months)						
1 - 4	66%	66%	4.67	3.72	4.50	2.85
6 - 7	17%	17%				
9 - 11	17%	17%				
Maternal Education (in years)						
10 - 12	50%	40%	12.50	1.52	13.30	1.75
13 - 16	50%	60%				
Maternal Age at Birth of Infant (in years)						
18 - 26	67%	40%	25.83	4.26	27.23	4.22
25 - 36	33%	60%				
Number of Siblings						
0	50%	60%	.50	.55	.60	.89
1 - 3	50%	40%				
Infant Sex						
Male	50%	50%				
Female	50%	50%				
Marital Status						
Married	100%	90%				
Single	-	10%				
Race						
White	100%	97%				
White-Black	-	3%				
City Data Collected						
Calgary	-	40%				
Edmonton	100%	60%				
Type of Feeding Observed						
Bottle	67%	53%				
Breast	-	27%				
Solids	33%	20%				

[a] N=6

[b] N=30

(t=1.02, df=34, p .20), infant age (t=.20, df=34, p .20), maternal education (t=1.04, df=34, p .20) and the number of older children in the family (t=.12, df=34, p .20).

In summary, the sample consists of six mother-SIDS siblings using the home monitoring intervention and a group of 30 mother-infant dyads from the general population. Although mothers in the normal sample are slightly older and tend to have more education, no significant differences between the normal and study samples were obtained on demographic variables.

Study Results

Home monitoring variables, maternal attribution of risk to the SIDS-sibling and HOME Inventory and NCAFS data are described for the six mother-SIDS sibling dyads. Comparisons of HOME and NCAFS data are made between mother-SIDS siblings and the normal group and between mother-SIDS siblings differing on home monitoring variables and attribution of infant risk. Maternal reports about the home monitoring experience and care of the SIDS-sibling are described.

Infant Age and Maternal Attribution of Risk

Table 3 delineates the risk category in which each SIDS-sibling was placed by the mother in relation to the infant's age and the age of the previous infant at the time of the SIDS death. Three mothers placed their infants in a slight risk category while three attributed large risk to the infant. Five mothers did not change the category of infant risk from the initial to final data collection visits, indicating some

Table 3

Maternal Attribution of Infant Risk at Initial and Final Data Collection Visits, Corresponding Infant Age and Age of Previous Baby at SIDS Death, for Each Case.

Case #		Attribution of Infant Risk	Age of Infant (in months)	Age of Previous Infant at SIDS Death (in months)
1	Time 1	Large	3.50	3.40
	Time 2	Slight	4.75	
2	Time 1	Large	1	2.75
	Time 2	Large	2	
3	Time 1	Large[a]	3[a]	1.30
	Time 2	Large	3	
4	Time 1	Slight	2	5.25
	Time 2	Slight	3	
5	Time 1	Slight[a]	3[a]	2.50
	Time 2	Slight	3	
6	Time 1	Slight	3.25	3.97
	Time 2	Slight	4.25	

Note. Time 1 and 2 refer to the initial and final data collection visits.

[a] Restrospective data - Mother's perception of risk when infant was 2-4 months old.

degree of stability over one month in the responses of this sample to the question about infant risk (see Appendix 3). Participant number one changed the risk category from large to slight. In this case, it should be noted, at Time 1 the infant was four days past the age at which the previous infant died and 1.25 months past this anniversary date at Time 2. The infant for participant number six also went through the anniversary age of the SIDS event and no change in the risk category occurred. Generally, there was no discernable pattern for this sample between maternal attribution of risk to the infant and infant age in relationship to the anniversary age of the SIDS event.

Attribution of Risk and Monitor Alarms

Maternal attribution of risk to the SIDS-sibling, maternal confidence in the accuracy of monitors and the frequency and type of recorded monitor alarms for each participant are presented in Table 4. Two participants recorded zero apnea/bradycardia episodes since home monitoring was initiated. Case four was the only participant who recorded apnea requiring vigorous stimulation during the data collection period. Case number three reported bradycardia treated with vigorous stimulation prior to the data collection period. No consistent patterns were revealed between apnea/bradycardia episodes and the risk attributed to the infant. However, it is interesting to note that infants with and without reported episodes of apnea/bradycardia were placed in both large and slight risk categories.

The frequency of looselead alarms recorded over one month varied from zero to 77. All participants reported frequent looselead alarms

Table 4

Maternal Attribution of Infant Risk at Initial and Final Data Collection Visits, Corresponding Confidence in Monitor Accuracy and Frequency of Monitor Alarms, for Each Case.

Case #		Attribution of Infant Risk	Confidence in Monitor Accuracy	Monitor Alarms		
				Apnea	Bradycardia	Loose Lead
1	Time 1	Large	Very Confident	0	1	77
	Time 2	Slight	Moderately Confident			
2	Time 1	Large	Very Confident	0	0	0
	Time 2	Large	Very Confident			
3	Time 1	Large[a]	Very Confident[a]	5	11	-[b]
	Time 2	Large	Very Confident			
4	Time 1	Slight	Very Confident	10	4	1
	Time 2	Slight	Very Confident			
5	Time 1	Slight[a]	Very Confident	2[c]	0	-[b]
	Time 2	Slight	Very Confident			
6	Time 1	Slight	Moderately Confident	0	0	0
	Time 2	Slight	Moderately Confident			

Note. Time 1 and 2 refer to initial and final data collecton visits.

[a] Restrospective data - Mother's perceptions of risk when infant was 2-4 months old.

[b] Not recorded.

[c] Uncertain if apnea or machine.

at the beginning of home monitoring. These alarms subsided as mothers became familiar with the monitor, usually within the first week. Participant number one was the exception to this statement. She recorded the dates, times and reasons for 77 looselead alarms over a period of 40 days. The 77 alarms were reported on 26 separate days with one to 15 alarms per day. Ninety percent of the alarms were attributed to the baby's restlessness. It is worth noting that this infant is the oldest in the sample still using the monitor and sleeps on a water bed. Two mothers no longer using the monitor reported frequent looselead alarms with older infants as the main reason for discontinuing the monitor.

Five participants reported feeling very confident about the accuracy of the monitor, while one case reported moderate confidence. In five cases the degree of confidence did not change between the initial and final data collection visits. This finding indicates some degree of stability over one month in the responses of this sample to the question about confidence in monitor accuracy (see Appendix 3).

Participant number five expressed uncertainty about the reasons for two intermittent monitor alarms. These alarms occurred prior to data collection and had not been recorded at the time of their occurrence. Three participants reported intermittent apnea alarms when infants were breathing normally. Discrepancies between monitor alarms and infant status were attributed to improperly setting the machine or positioning the monitor belt. Generally, mothers felt if the apnea monitor was managed properly, the monitor would relay accurate information about the infant's status.

In summary, mothers generally expressed confidence about monitor accuracy regardless of the category of infant risk or the frequency and type of monitor alarms. As well, the degree of infant risk did not reveal any pattern with type and frequency of monitor alarms.

Variables Differentiating Dyads in Large and Slight Risk Categories

Three participants placed their infants in a large risk category and three attributed slight risk to the infant. Further analysis, as presented in Table 5, demonstrated a consistent pattern between the category of infant risk and the following variables: The number of months since the death of the previous infant from SIDS, the HOME Inventory scores and the NCAFS (interaction) scores. Participants who experienced the SIDS event 24 to 35 months previously, placed infants in a large risk category; those who experienced the SIDS event 13 to 19 months previously, attributed slight risk to their infants. HOME Inventory and NCAFS scores were consistently higher when more months had elapsed since the SIDS death and for infants placed in the large risk category. All infants in the large risk category were male, whereas infants in the slight risk category were all female.

Mann-Whitney U tests (one-tailed) for small sample sizes were computed to determine if significant differences on these measures and demographic variables existed between the large and slight risk dyads. The results of the statistical contrasts are presented in Table 6. Mean scores indicate participants who placed infants in a large risk category tended to be older, had more education, used the monitor for more hours per day and waited longer after the death of their infant to

Table 5

NCAFS and HOME Inventory Scores According to Maternal Attribution of Infant Risk and Months Elapsed Since the SIDS Death.

Age of Infant (in months)	Perception of Infant Risk	Months Since SIDS Event	HOME Score	NACF Score
4	Large	35	37	64
1	Large	32	36	66
11	Large[a]	24	36	61.5
2	Slight	19	27	52
7	Slight[a]	17	25	54.5
3	Slight	13	24	57.5

Note. Higher NCAFS and HOME Scores indicate more favorable interactions and home environments, respectively.

[a] Restrospective data - Mother's perception of infant risk when infant was 2-4 months of age.

Table 6

Statistical Contrasts on Demographic Variables, Home Monitoring Variables, and NCAFS and HOME Scores for Mothers Attributing Large Versus Slight Infant Risk.

	Perceived Infant Risk					
	Slight Risk		Large Risk			
Comparison[a]	Mean	SD	Mean	SD	P Level	
Infant Age (in months)	4.00	2.70	5.30	5.10	NS[d]	.50
Maternal Age at Birth of Infant (in years)	23	1.00	28.70	4.50		.10
Maternal Education (in years)	11.67	1.15	13.00	2.00	NS	.10
Apnea/Bradycardia Episodes	5.33	7.57	5.67	8.96	NS	.65
Months Since Occurrence of SIDS Death	16.33	3.06	30.33	5.69	S[e]	.05
Months Between SIDS Death and Birth of Subsequent Infant	12.33	4.04	25.00	10.39	NS	.10
Hours Per Day of Monitor Use[f]	11.50	2.35	13.54	.66	--	
Total HOME Inventory Score	25.33	1.53	36.33	.58	S[e]	.05
Total NCAFS Score	54.67	2.75	63.83	2.25	S[e]	.05

Note. Higher NCAFS and HOME Scores indicate more favorable interactions and home environments.

[a] N=6; $n_1=3$; $n_2=3$.
[c] Statistical contrasts determined by Mann-Whitney U Test.
[d] NS=non-significant difference.
[e] S=significant difference, one-tailed test.
[f] N=4, Statistical contrast not determined.

have another baby. Infants in the large risk category tended to be slightly older.

No significant differences between the slight and large risk participants were obtained for infant age (U=4, p=.50), maternal education (U=1, p=.1), apnea/bradycardia episodes (U=5, p=.65), the number of months between the SIDS death and the birth of the subsequent infant (U=1, p=.1), or maternal age at the birth of the infant (U=1, p=.1). Significant differences (U=0, p=.05, large risk > slight risk) were obtained for the number of months since the SIDS event, the Total HOME Inventory score and the Total NCAF score between dyads in the slight and large risk categories.

Mother-Infant Interaction and the Home Environment

HOME Inventory and NCAFS data were examined to determine: General patterns for mother-SIDS sibling dyads, differences between mother-SIDS siblings and the normal group and differences between dyads who placed infants in large and slight risk categories.

General Patterns of Interaction and Home Environments

Table 7 presents descriptive information on the feeding interactions. None of the participants breast fed their infant. Four mothers bottle fed and two did solid feeding for the observations. Scores on the Response to Distress subscale were based on at least one episode of distress for all dyads.

Three mothers expressed concerns about the feeding or eating of the infant. The mean score for mothers expressing concerns was 60 (n = 3) and for mothers with no concerns, 58.5 (n = 3). This difference

Table 7

Descriptive Information About the Feeding Observations.

	Frequency of Mothers for Each Observation	
Descriptive Category	Observation 1	Observation 2
Type of Feeding:		
Bottle	3	3
Bottle and solid	1	1
Breast	0	0
Solids	2	2
Length of Feeding (in min.)		
Less than 10	0	0
10 - 20	1	2
21 - 30	4	2
More than 30	1	2
Infant Distress During Feeding		
Yes	4	5
No	2	1
Maternal Concerns About Feeding		
Yes	2	1
No	4	5
Presence of Other Sibling		
Yes	2	3
No	4	3
Maternal Discomfort Due to Presence of Observer		
Yes	1	0
No	5	6
Is This a Typical Feeding?		
Yes	6	5
No	0	1

between mean scores, using a Mann-Whitney U test, was not significant (U=4, p=.5, one-tailed). All three mothers who expressed no concerns about feeding had one older child. No significant difference (U=3, p=.35, one-tailed) was obtained between the mean score of 58.83 for feeding interactions done with older siblings present and the mean score of 60.67 for dyads with no older siblings.

Five of the six participants reported the feeding as typical for both observations. One mother reported new infant behaviors for one of the feeding observations. Five participants reported no feelings of discomfort due to the presence of an observer for both observations. One mother reported discomfort for the first but not the second observation.

Table 8 presents the mean subscores, total scores and standard deviations of the two NCAFS observations for each participant. The child scores revealed less variation between observations than parent and total scores. The subscale, Cognitive Growth Fostering appears to have the least variation of the Parent subscales. Of the 76 behavioral items, changes in "yes/no" responses from Observation 1 to 2 occurred on six to twelve items for each mother-infant dyad.

Figure 2 compares in graph form, the total NCAFS score of each participant for Observation 1 and 2. Total NCAFS scores varied one to four points between observation one and two for five dyads. During the second observation, participant number four reported new infant behaviors, to which she had not yet become accustomed. This asynchrony revealed itself in a lower subscore on Maternal Response to Distress and hence a lower total score. This example emphasizes the importance

Table 8

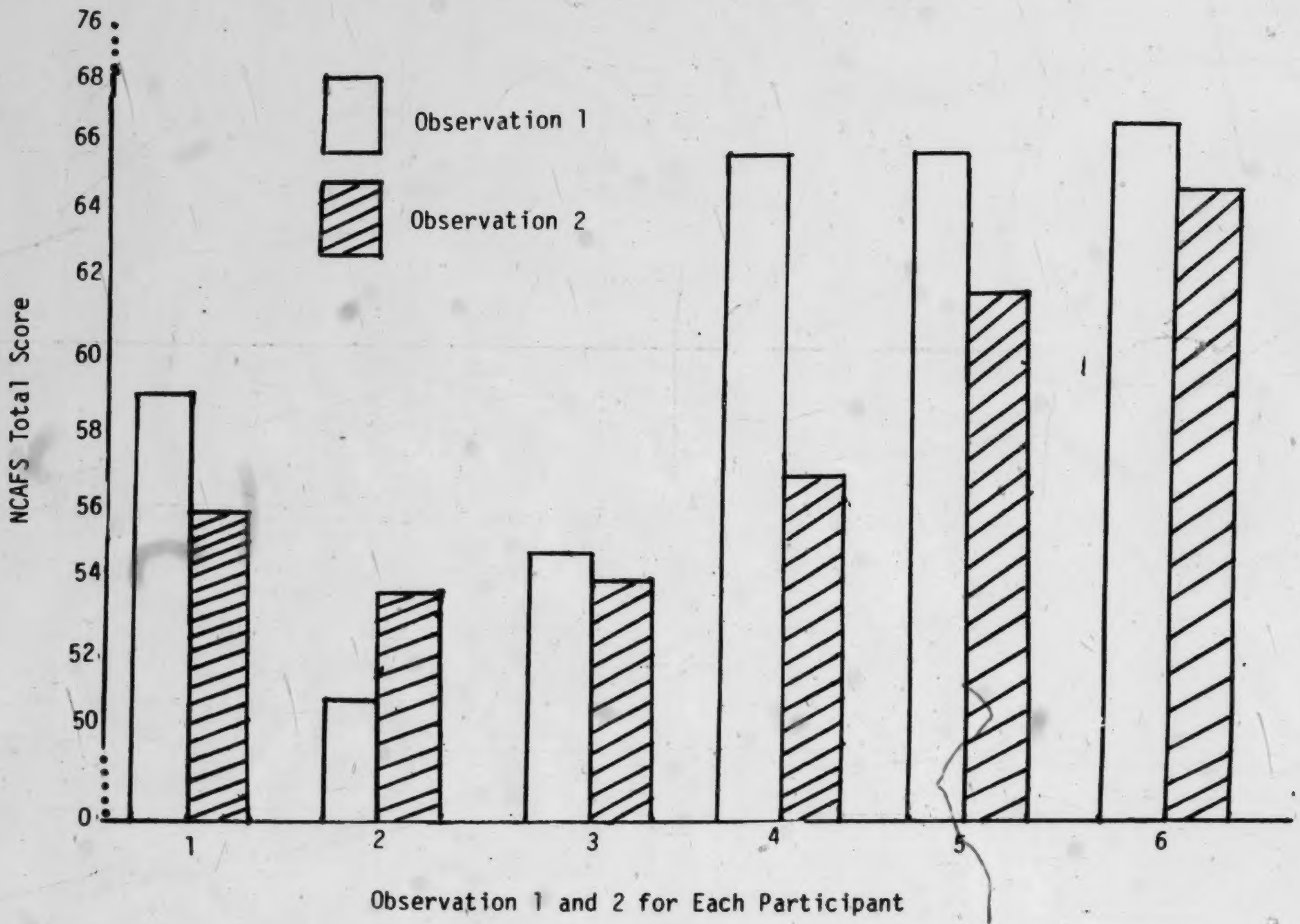
Total and Subscale NCAFS Mean and Standard Deviations for Each Participant.

	Participant Number					
Subscale[a]	1	2	3	4	5	6
I. Sensitivity to Cues						
Mean	10.50	11.50	12.50	12.50	13.50	12.50
SD	2.12	.71	.71	.71	.71	.71
II. Response to Distress						
Mean	10.50	10.00	6.00	8.00	10.50	10.00
SD	.71	1.41	1.41	4.24	.71	0
III. Social-Emotional Growth Fostering						
Mean	11.00	10.50	11.50	13.50	12.00	13.00
SD	1.41	.71	.71	.71	1.41	0
IV. Cognitive Growth Fostering						
Mean	5.50	4.00	4.50	4.00	7.50	9.00
SD	.71	0	.71	0	.71	0
Total Parent						
Mean	37.50	36.00	34.50	38.00	43.50	44.50
SD	2.12	0	3.54	4.24	3.54	.71
V. Clarity of Cues						
Mean	11.00	11.50	13.00	15.00	13.50	13.00
SD	0	.71	1.41	0	.71	1.41
VI. Response to Parent						
Mean	9.00	4.50	7.00	8.50	7.00	8.50
SD	0	.71	1.41	.71	0	.71
Total Child						
Mean	20.00	16.00	20.00	23.50	20.50	21.50
SD	0	1.41	2.83	.71	.71	.71
Total Score						
Mean	57.50	52.00	54.50	61.50	64.00	66.00
SD	2.12	1.41	.71	6.36	2.83	1.41

[a] Possible Range of Scores:

I 0-16
II 0-11
III 0-14
IV 0- 9
V 0-15
VI 0-11
Total Parent 0-50
Total Child 0-26
Total 0-76

Figure 2. Bar Graph of Total NCAFS Scores by Participant and Observation Number.



of determining if feedings are typical and points to the value of doing more than one observation when dyads are experiencing a developmental change.

Out of a possible score of 76, mean Total NCAFS scores ranged from 52 to 66. The mean NCAFS score for the total group was 59.25 with a standard deviation of 5.50.

All participants reported their infants to be growing and developing normally. Table 9 presents the total scores and subscores of each participant on the HOME Inventory. Out of a possible score of 45, Total HOME scores ranged from 24 to 37 with a mean of 30.83 and a standard deviation of 6.1.

Differences Between Study and Normal Samples on HOME and NCAFS Data

The means, standard deviations and results of statistical contrasts between mother-SIDS sibling and normal dyads on NCAFS and HOME Inventory scores are presented in Table 10. Higher scores are more favorable. Statistical contrasts were computed using the Mann-Whitney U test, for small sample sizes. The 30 scores for the normal sample were split into six scores. Each score represented the mean NCAFS and HOME scores for five subjects most closely matched on demographic variables to one of the mother-SIDS sibling dyads.

A significant difference was revealed in favor of the normal group on the NCAF Subscale, Mother's Sensitivity to Infant Cues (U=6, p=.013, one-tailed or .026, two-tailed). Differences in favor of the normal group were obtained on the Total Parent score, Response to Distress, and the Total NCAFS score but these differences were not significant (p=.16 to .20, one-tailed).

Table 9

Total and Subscale HOME Inventory Scores for Each Participant.

	Participant Number					
Subscale[a]	1	2	3	4	5	6
I. Maternal Responsivity	9	6	9	10	11	10
II. Avoidance of Restriction	6	7	2	4	7	6
III. Organization of Environment	3	6	2	5	4	6
IV. Appropriate Play Materials	4	5	5	9	6	6
V. Maternal Involvement	2	2	3	6	6	6
VI. Variety of Daily Stimulation	1	1	3	2	3	2
Total Score	25	27	24	36	37	36

Note: Higher scores indicate more favorable environments.

[a] Possible Range of Scores:

I	0-11
II	0- 8
III	0- 6
IV	0- 9
V	0- 6
VI	0- 5
Total	0-45

Table 10

Statistical Contrasts Between Study and Normal Samples on HOME Inventory and NCAFS Scores.

Subscales	Sample					
	Study Sample[a]		Normal Sample[b]			
	Mean	SD	Mean	SD	P Level[c]	
NCAF Scales						
Sensitivity to Cues	12.17	1.03	13.80	1.65	S[d]	.01
Response to Distress	9.17	1.81	10.13	.94	NS[e]	.20
Soc-Emot Growth Fostering	11.92	1.16	12.03	1.52	NS	.53
Cognitive Growth Fostering	5.57	2.07	6.60	1.71	NS	.24
Clarity of Cues	12.87	1.46	12.57	1.89	NS	.45
Response to Parent	7.42	1.66	7.63	1.69	NS	.41
Total Parent Score	39.00	5.96	42.57	3.87	NS	.16
Total Child Score	20.25	2.47	20.20	3.18	NS	.45
Total NCAFS Score	59.25	5.50	62.77	5.46	NS	.20
HOME Inventory Scales						
Maternal Responsivity	9.17	1.72	9.87	1.31	NS	.294
Avoidance of Restriction	5.33	1.97	7.17	.70	S	.008
Organization of Environment	4.33	1.63	5.30	.65	NS	.197
Appropriate Play Materials	5.83	1.72	6.47	1.89	NS	.197
Maternal Involvement	4.17	2.04	5.27	1.26	NS	.090
Variety Daily Stimulation	2.00	.89	3.0	1.08	NS	.197
Total Home Score	30.83	6.10	37.07	4.38	S	.032

Note: Higher scores indicate more favorable interactions and environments.

[a] N=6.

[b] N=30.

[c] Statistical contrasts computed using the Mann-Whitney U Test.

[d] S=Significant difference, one-tailed test.

[e] NS=Non-significant difference.

Significant differences in favor of the normal group were obtained on the HOME Inventory subscale, Avoidance of Restriction and Punishment (U=3, p=.008, one-tailed, or .026, two-tailed). Significant differences were not obtained on other subscales. However, all subscale mean differences were in favor of the normal group, with Maternal Involvement revealing the largest difference (U=9, p=.09, one-tailed or .18, two-tailed) and Maternal Responsivity revealing the least significant difference (U=14, p=.249, one-tailed or .588, two-tailed).

Differences on HOME and NCAFS Data According to Risk Category

NCAFS mean scores, standard deviations and results of statistical contrasts between mothers attributing large versus slight risk to SIDS-siblings are presented in Table 11. Higher scores indicate more favorable interactions. Significant differences (U=0, p=.05, one-tailed) in favor of dyads in the large risk category were obtained on Mother's Social-Emotional Growth Fostering Behaviours, the Total Parent score, Total Child score and the Total NCAFS score. The mean scores for dyads in the large risk category were higher on all subscales, with largest non-significant differences revealed on Mother's Sensitivity to Cues and the Clarity of Infant Cues (U=1, p=.1, one-tailed). Least significant differences were obtained for Mother's Response to Distress and the Infant's Responsiveness to the Parent (U=1, p=.5, one-tailed).

Interaction observations were rescored using the factors and items obtained from the factor analysis of the NCAFS instrument (Bee, 1981). Items based on factor loadings were considered a reliable, alternative method of determining differences in the characteristics of interaction

Table 11

Statistical Contrasts on NCAFS Total and Subscale Scores Between Mothers Attributing Large Versus Slight Infant Risk.

	Risk Group[a]					
	Large Risk		Slight Risk			
NCAF Subscales	Mean	SD	Mean	SD	P Level[b]	
Sensitivity to Cues	12.83	.58	11.50	1.00	NS[c]	.10
Response to Distress	9.50	1.32	8.83	2.47	NS	.50
Soc-Emot Growth Fostering	12.83	.75	11.00	.50	S[d]	.05
Cognitive Growth Fostering	6.83	2.57	4.67	.76	NS	.35
Clarity of Cues	13.83	1.04	11.83	1.04	NS	.10
Response to Parent	8.00	.87	6.83	2.25	NS	.50
Total Parent Score	42.00	3.5	36.00	1.50	S	.05
Total Child Score	21.83	1.53	18.67	2.31	S	.05
Total NCAFS Score	63.83	2.25	54.67	2.75	S	.05

Note: Higher scores indicate more favorable mother-infant interactions.

[a] $N=6$; $N_1=3$; $N_2=3$.
[b] Statistical differences determined by the Mann-Whitney U Test.
[c] NS=Non-significant difference.
[d] S=Significant difference, one tailed test.

between mother-infant dyads in the large and slight risk categories. The mean scores, standard deviations and results of statistical contrasts on factor scores between dyads in the large and slight risk categories are presented in Table 12. Significant differences (U=0, p=.05, one-tailed) were obtained in favor of the large risk group on the Total Factor Score and Factor 1, Parent Verbalization. No other differences were significant. However, mean scores were higher on all factors for dyads in the large risk category. Tactile Stimulation revealed the largest difference (U=2, p=.2, one-tailed). Positive Child Cues, Optimum Positioning, Parent Responds to Child Food Cues and Avoidance of Criticism revealed the least significant differences between the risk groups (U=4, p=.50, one-tailed).

Means, standard deviations and the results of statistical contrasts on HOME Inventory scores between dyads in the large and slight risk category are presented in Table 13. Higher scores indicate more favorable environments. Significant differences (U=0, p=.05, one-tailed) in favor of the large risk group were obtained on Emotional and Verbal Responsivity of the Mother, Provision of Appropriate Play Materials, Maternal Involvement and the Total HOME Inventory score. No other significant differences were found, although the trend was the same as NCAFS scores, with dyads in the large risk category obtaining higher mean scores on all subscales.

From the data presented in Tables 12 and 13, it is apparent that styles of interaction and the stimulation available to the infant in the home environment differed for dyads according to maternal attribution of risk to the SIDS-sibling. Further exploration of these

Table 12

Statistical Contrasts on Factored NCAFS Scores Between Mothers Attributing Large Versus Slight Infant Risk.

NCAFS Factors	Risk Group[a]					
	Large Risk		Slight Risk			
	Mean	SD	Mean	SD	P Level[b]	
Parent Verbalization (Possible Score=13)	11.67	.58	7.83	1.89	S[c]	.05
Positive Child Cues (Possible Score=8)	6.17	1.76	5.33	3.40	NS[d]	.50
Tactile Stimulation (Possible Score=8)	6.00	3.04	4.83	3.33	NS	.20
Optimum Positioning (Possible Score=6)	5.50	.5	5.33	.58	NS	.50
Child Hunger Signals (Possible Score=6)	3.50	.5	2.33	2.08	NS	.35
Parent Responses to Food Cues (Possible Score=6)	4.83	1.26	4.50	1.32	NS	.50
Avoidance of Criticism (Possible Score=4)	3.67	.58	3.5	.87	NS	.50
Mutual Eye Contact (Possible Score=4)	4.0	0	3.83	.29	NS	.35
Total Score (Possible Score=53)	45.33	1.53	37.67	2.75	S	.05

Note: Higher scores indicate a more favorable interaction.

[a] $N=6$; $N_1=3$; $N_2=3$.

[b] Statistical differences determined by the Mann-Whitney U Test.

[c] S=Significant difference, one tailed test.

[d] NS=Non-significant difference.

Table 13

Statistical Contrasts on HOME Inventory Total and Subscale Scores Between Mothers Attributing Large Versus Slight Infant Risk.

	Risk Group[a]					
	Large Risk		Slight Risk			
HOME Subscales	Mean	SD	Mean	SD	P Level[b]	
Maternal Responsivity	10.33	.58	8.00	1.73	S[c]	.05
Avoidance of Restriction	5.67	1.53	5.00	2.65	NS[d]	.50
Organization of Environment	5.00	1.00	3.67	2.08	NS	.35
Appropriate Play Materials	7.00	1.73	4.67	.58	S	.05
Maternal Involvement	6.00	0	2.33	.58	S	.05
Variety Daily Stimulation	2.33	.58	1.67	1.15	NS	.35
Total HOME Score	36.33	.58	25.33	1.53	S	.05

Note: Higher scores indicate more favorable home environments.

[a] $N=6$; $N_1=3$; $N_2=3$.
[b] Statistical differences determined by the Mann-Whitney U Test.
[c] S=Significant difference, one tailed test.
[d] NS=Non-significant difference.

differences was done by comparing dyads in the large and slight risk categories to dyads in the normal group. The normal group consisted of 14 mother-infant dyads matched to the ages of the three SIDS-siblings in each risk category.

Table 14 presents the results of statistical contrasts on NCAFS and HOME Inventory data between the normal group and dyads with SIDS-siblings in the slight risk category. Mean score differences were in favor of the normal group on all NCAFS and HOME subscales. Significant differences using the Mann-Whitney U test (U=0, p=.05, one-tailed) were obtained on the NCAF scales, Mother's Sensitivity to Infant Cues, the Total Parent score, the Total NCAFS score and on the HOME subscales, Maternal Involvement and Total HOME score.

Results of statistical contrasts on HOME and NCAFS data between the normal group and dyads with SIDS-siblings in the large risk category are presented in Table 15. A significant difference in favour of the normal group (U=0, p=.05, one-tailed) was obtained on the Total HOME score. No other significant differences between these groups were obtained. However, mean score differences were in favor of mother-SIDS siblings on several subscales, including: Clarity of Cues, Infants' Responsiveness to Parent, the Total Child NCAFS score and the HOME subscale, Maternal Involvement.

Significant differences indicated that dyads with SIDS-siblings in the slight risk category exhibited a style of interaction that was more technical, with fewer social occasions during the feeding, than dyads in the normal group. As well, these mothers were less sensitive to

Table 14

Statistical Contrasts on HOME Inventory and NCAFS Total and Subscale Scores Between the Normal Sample and Mother-SIDS Siblings in the Slight Risk Category.

	Sample[a]					
	SIDS-Sibling Dyads		Normal Dyads			
Subscales	Mean	SD	Mean	SD	P Level[b]	
NCAF Scales						
Sensitivity to Cues	11.50	1.00	14.20	.53	S[c]	.05
Response to Distress	8.83	2.47	10.53	.12	NS[d]	.10
Soc-Emot Growth Fostering	11.00	.50	12.00	.60	NS	.10
Cognitive Growth Fostering	4.67	.76	5.87	1.10	NS	.10
Clarity of Cues	11.83	1.04	12.53	.83	NS	.20
Response to Parent	6.83	2.25	7.87	.95	NS	.50
Total Parent Score	36.00	1.50	42.60	1.51	S	.05
Total Child Score	18.67	2.31	20.40	1.78	NS	.20
Total NCAFS Score	54.67	2.75	62.15	2.97	S	.05
HOME Inventory Scales						
Maternal Responsivity	8.00	1.73	9.53	.95	NS	.20
Avoidance of Restriction	5.00	2.65	7.20	.20	NS	.10
Organization of Environment	3.67	2.08	5.27	.50	NS	.35
Appropriate Play Materials	4.67	.58	5.93	1.33	NS	.20
Maternal Involvement	2.33	.58	5.13	.70	S	.05
Variety Daily Stimulation	1.67	1.15	2.60	.72	NS	.20
Total HOME Score	25.33	1.53	35.67	4.05	S	.05

Note: Higher scores indicate more favorable interactions and home environments.

[a] N=6; $n_1=3$; $n_2=3$.

[b] Statistical contrasts were determined using the Mann-Whitney U test.

[c] S=Significant difference, one-tailed.

[d] NS=Non-significant difference.

Table 15

Statistical Contrasts on HOME Inventory and NCAFS Total and Subscale Scores Between the Normal Group and Mother-SIDS Siblings in the Large Risk Category.

	Sample[a]					
	SIDS-Sibling Dyads		Normal Dyads			
Subscales	Mean	SD	Mean	SD	P Level[b]	
NCAF Scales						
Sensitivity to Cues	12.83	.58	13.40	1.31	NS	.35
Response to Distress	9.50	1.32	9.73	.70	NS	.50
Soc-Emot Growth Fostering	12.83	.76	12.06	1.03	NS	.20
Cognitive Growth Fostering	6.83	2.57	7.33	.12	NS	.35
Clarity of Cues	13.83	1.04	12.60	1.56	NS	.20
Response to Parent	8.00	.87	7.40	.72	NS	.50
Total Parent Score	42.00	3.50	42.53	2.14	NS	.50
Total Child Score	21.83	1.53	20.00	2.27	NS	.20
Total NCAFS Score	63.83	2.25	62.53	1.03	NS	.20
HOME Inventory Scales						
Maternal Responsivity	10.33	.58	10.20	.72	NS	.50
Avoidance of Restriction	5.67	1.53	7.13	.31	NS	.35
Organization of Environment	5.00	1.00	5.33	.12	NS	.35
Appropriate Play Materials	7.00	1.73	7.00	1.04	NS	.50
Maternal Involvement	6.00	-	5.40	.87	NS	.20
Variety Daily Stimulation	2.33	.58	3.40	.72	NS	.10
Total HOME Score	36.33	.58	38.47	1.21	S	.05

Note: Higher scores indicate more favorable interactions and home environments.

[a] N=6; n_1=3; n_2=3.

[b] Statistical contrasts were determined using the Mann-Whitney U test.

[c] S=Significant difference, one-tailed.

[d] NS=Non-significant difference.

cues indicating hunger, satiation and the infant's readiness to interact or disengage. Conversation tended to center around food intake, burps and cleanliness. In comparison to the normal group, mothers attributing slight risk to infants, noticed social aspects of the infant's behavior less often and spent less time trying to elicit social responses.

In contrast, mothers attributing large risk to SIDS-siblings provided as much or more social stimulation during feeding compared to mothers in the normal group. However, similar to dyads in the slight risk category, a lower mean score was obtained on Mother's Sensitivity to Infant Cues in comparison to the normal group.

Mothers with infants in the slight risk category were less likely to be involved in promoting the SIDS-sibling's development in comparison to the normal group; while mothers attributing large risk to infants were more likely than the normal group to be involved in growth-fostering activities with the SIDS-sibling during the course of daily activities.

NCAFS and HOME Inventory Scores for Dyads Differing on Demographic Characteristics

Statistical analyses were done to determine what, if any, demographic variables may have influenced differences on NCAFS and HOME Inventory scores between dyads in the large and slight risk categories. The direction and significance of NCAFS and HOME differences based on demographic variables were compared across the following three groups: (a) Six mother-SIDS sibling dyads; (b) The 30 normal mother-infant dyads from the general population; (c) Six mother-infant dyads matched to the six mother-SIDS siblings on several demographic variables. Table 16 presents a comparison of the demographic characteristics of the SIDS-sibling and matched group for each participant.

Statistical contrasts were calculated using a two-tailed student's t test for independent groups with separate variances for the normal group and the Mann-Whitney U test, one-tailed for small sample sizes for the SIDS-sibling and matched dyads. Differences on subscale scores that were significant and in the same direction in at least two of the three groups, including the normal sample, were considered more likely influenced by the corresponding demographic characteristic.

Infant Age

Statistical contrasts on NCAFS and HOME Inventory subscores and total scores were computed for: (a) Mother-SIDS siblings aged one to three versus four to eleven months; (b) a matched sample with infants aged one to three and four to eleven months; (c) and the normal dyads for infants one to four versus five to eleven months. Significant differences were obtained for the normal group in favor of older infants for the NCAF subscale, Clarity of Infant Cues (t=2.55, df=28, p=.017) and the Total Child score (t=2.28, df=28, p=.032). Although differences were not significant for the SIDS-sibling and matched groups, mean score differences were also in favor of older infants on Clarity of Infant Cues for both groups (U=1, p=.1, one-tailed) and on the Total Child score (U=1, p=.1, one-tailed) for the matched group.

The consistency among the three groups in the direction and

Table 16

Demographic Characteristics of Mother - SIDS Sibling Dyads and Matched Mother-Infant Dyads for Each Participant.

	Demographic Characteristics											
Participant No.	Infant Age (in months)		Infant Sex		Maternal Age (in years)		Maternal Education (in years)		Other Children		Marital Status	
	SIDS	Matched	SIDS	Matched	SIDS	Matched	SIDS	Matched	SIDS	Matched	SIDS	Matched
1	11	11	M	M	24	25	12	11	0	0	M	M
2	3	2	F	F	23	22	11	10	1	1	M	M
3	7	7	F	F	22	23	11	12	0	0	M	M
4	2	3	F	F	24	26	13	14	1	0	M	M
5	1	1	M	M	29	28	13	15	1	0	M	M
6	4	4	M	M	33	31	15	16	0	0	M	M

significance of differences indicates that older infants are more likely to obtain higher scores on Child Subscales. Differences on other NCAF scales were inconsistent in the significance level or direction among the three groups.

Significant differences in favor of older children were obtained on the following HOME Inventory subscales: Maternal Responsivity for the normal group (t=3.37, df=27, p=.002) and the matched group (U=0, p=.05); Provision of Appropriate Play Materials for the normal group (t=3.65, df=27, p=.001) and the matched group (U=0, p=.05); Variety in Daily Stimulation for the normal group (t=2.53, df=14, p=.024) and matched group (U=0, p=.05); and the Total HOME Inventory score for the normal group (t=3.13, df=25, p=.005) and the matched group (U=0, p=.05). Although differences on these subscales were not significant for the SIDS-sibling group, the direction of mean score differences was in favor of older infants.

The mean infant age for dyads in the large risk category was slightly, although not significantly older (5.33 versus 4.00, U=4, p=.50, one-tailed). NCAFS and HOME scores which tended to be higher for older infants were examined to determine patterns according to infant age in the SIDS-sibling group. This was done by ranking scores from lowest to highest and comparing ranks to infant age and risk category. Table 17 presents the age and risk category for each SIDS-siblilng and the rank of each SIDS-sibling's HOME and NCAFS scores in relation to the rest of the group. The highest score obtained by the dyad in the SIDS-sibling group was given a rank of 6 and the lowest score a rank of 1. If more than one dyad obtained the same score the

Table 17

Infant Age, Corresponding Risk Category and Ranks on NCAFS and HOME Inventory Scores for Each Participant.

		NCAF Subscales			
Infant Age (in Months)	Risk Category	Clarity of Cues Rank	Total Child Rank	Total Parent Rank	Total Score Rank
1 Month	Large	3.5	5	6	6
2 Months	Slight	2	1	1	1
3 Months	Slight	1	2.5	3	3
4 Months	Large	5	4	5	5
7 Months	Slight	3.5	2.5	2	2
11 Months	Large	6	6	4	4

		HOME Subscales		
Infant Age (in Months)	Risk Category	Play Materials Rank	Maternal Responsivity Rank	Total Score Rank
1 Month	Large	4.5	4.5	4.5
2 Months	Slight	2.5	1	3
3 Months	Slight	1	2.5	2
4 Months	Large	4.5	6	6
7 Months	Slight	2.5	2.5	1
11 Months	Large	6	4.5	4.5

[a] Rank 1=lowest score in the group; Rank 6=highest score in the group.

average rank was given to both dyads.

Both the oldest and youngest infants were placed in the large risk category. Ranks on NCAFS scores indicated that regardless of infant age, dyads in the large risk group consistently obtained higher scores than infants in the slight risk category on Clarity of Cues, Total Child, Total Parent and the Total NCAFS scores. However, the oldest infant in the large risk category obtained the highest score on Clarity of Cues and the Total Child score for that group. Similarly, the oldest infant in the slight risk category obtained the highest score on Clarity of Cues for that group. Based on ranks, high and low Total NCAFS scores varied directly with high and low Total Parent scores, but not necessarily with the Total Child score.

Similar patterns were revealed on HOME Inventory scores. Regardless of the age of the infant, higher scores were obtained for infants in the large risk category on Provision of Appropriate Play Materials, Maternal Responsivity and the Total HOME score. The oldest infant in the group obtained the highest score on Provision of Appropriate Play Materials but not on Maternal Responsivity or the Total score. The infant who obtained the lowest Total HOME score was three to six months older than four other infants and was in the slight risk category.

In summary, older infants tended to have higher scores on Clarity of Cues, the Total Child NCAFS and Provision of Appropriate Play Materials. However, from the evidence presented, it seems likely in this SIDS-sibling sample, factors other than infant age have also influenced mean score differences between dyads in the large and slight risk categories.

Infant Sex

In the SIDS-sibling group, infants placed in the large risk category were male, whereas infants in the slight risk group were female. Consequently, differences on HOME and NCAF scales between risk groups were also obtained for male versus female infants. Statistical analyses on the normal and matched groups indicated that male/female differences were likely due to chance.

Significant differences were obtained for the SIDS-sibling group in favour of males on the NCAF scales: Social-Emotional Growth Fostering, Total Parent score, Total Child score, and the Total NCAFS score (U=0, p=.05, one-tailed). Differences on these subscales for the normal and matched groups were computed as follows: Social-Emotional Growth Fostering for the normal group (t=1.39, df=27, p=.179) and the matched group (U=4, p=.5, one-tailed); Total Parent score for the normal group (t=.05, df=26, p=.963) and the matched group (U=4, p=.50, one-tailed); Total Child score for the normal group (t=.34, df=27, p=.737) and the matched group (U=1, p=.1, one-tailed) and the Total NCAFS score for the normal group (t=.23, df=26, p=.820) and for the matched group (U=3, p=.35, one-tailed). As well as being non-significant, the direction of differences for the normal group was in favor of females.

Differences between males and females on HOME subscales revealing significant differences in the SIDS-sibling group were computed for the normal and matched samples. Results were as follows: Maternal Responsivity for the normal group (t=1.42, df=27, p=.166) and for the matched group (U=4, p=.50, one-tailed); Provision of Appropriate Play

Materials for the normal group (t=1.59, df=27, p=.125 and the matched group (U=3, p=.35, one-tailed); Maternal Involvement for the normal group (t=.57, df=27, p=.571) and the matched group (U=3, p=.35); and the Total HOME score (t=1.82, df=27, p=.081) for the normal group and (U=4, p=.5, one-tailed) for the matched sample. These differences were in favor of males but were not statistically significant. In summary, male/female differences on NCAFS and HOME scores are concluded more likely due to chance.

Maternal Education

Statistical contrasts on NCAFS and HOME scores for the three groups between mothers with 12 or less years and 13 or more years of education were computed. No significant differences (p=.05) on subscales were obtained for mother-SIDS siblings, matched dyads or the normal group. However, as indicated in Table 6, mothers tended to have more education in mother-SIDS sibling dyads exhibiting more favorable interactions.

Maternal Age

No significant differences on NCAFS and HOME Inventory scores were obtained (p=.05) between mothers aged 18 to 26 and 27 to 35 years. As indicated in Table 6, mothers tended to be older in mother-SIDS sibling dyads obtaining more favorable interaction scores.

Number of Children in the Family

Consistent significant differences were not obtained on NCAFS and HOME scores between dyads in the three groups with one or more older children and dyads with no older children. It is worth noting, however, that the SIDS death occurred with the first-born child in dyads who obtained more favorable interaction scores; whereas in two of the three dyads exhibiting less favorable interactive behaviors, the

SIDS death occurred with the second born-infant.

In summary, the cumulative effect of maleness in subsequent SIDS siblings, older mothers with slightly more education and no surviving children in the family prior to the SIDS death may have influenced significant differences obtained on HOME Inventory and NCAFS scores in favor of mother-SIDS sibling dyads in the large risk category. Dyads with older infants tended to obtain higher scores on Clarity of Infant Cues, the Total Child score and Provision of Appropriate Play Materials. Differences according to infant age in the SIDS-sibling group were more apparent within risk groups rather than for the total group suggesting that factors other than infant age also contributed to significant differences between dyads in the large and slight risk categories.

Maternal Reports About Home Monitoring and Care of the SIDS-Sibling

Table 18 presents the frequency of mothers expressing concerns about infant care, infant behavior, monitor mangement and life circumstances according to the category of infant risk.

Concerns of Mothers Attributing Large Risk to the SIDS-Sibling

Concerns about infant behavior and infant care are expressed by more mothers with SIDS-siblings in the large risk category than slight risk category. More mothers attributing large risk had concerns about: Travel with the infant; supervision while driving in a car; trips outside of the home; separation from the infant; putting the infant down to sleep; disruption of usual routines; and changes in infant's eating and activity patterns. Reluctance to purchase or accept items that could be considered for future use such as clothing

Table 18

Frequency of Mothers With Concerns About the SIDS-Sibling, Monitor Management and Life Circumstances According to Maternal Attribution of Infant Risk.

Maternal Concerns	Attribution of Infant Risk: Large Risk (Maternal Frequency)	Attribution of Infant Risk: Slight Risk (Maternal Frequency)
Infant Care		
Travelling	2	0
Driving	2	0
Trips outside home	1	0
Separation	3	0
Putting infant down to sleep	2	0
Disruption of infant's routines	2	1
Supervision in others' homes	2	1
Infant Behavior		
Changes in eating patterns	1	0
Changes in sleeping patterns	3	2
Respiratory infections	3	3
Activity level and responsiveness	1	0
Monitor Management		
Number of loose lead alarms	1	0
Tightness of monitor belt	1	0
Difficulty hearing loose lead alarms	2	0
Discontinuing the monitor in the future	3	0
Life Circumstances		
Feeling physically isolated	2	2
Feeling emotionally isolated	2	2
Finding a babysitter	3	2
Unemployment of spouse	0	2
Financial difficulties	0	2
Illness of a family member	0	1
Father absence from the home	0	1
Behavioral problems with older siblings	0	2
Reluctance to receive or purchase items for future use	2	0
Disappointment in sex of SIDS-sibling	0	1
Carrying most of the responsibility for infant care	1	3

or toys beyond the infant's age was also expressed by mothers attributing large risk to SIDS-siblings. Concerns expressed about monitor management for this group included: Difficulty hearing loose-lead alarms; apprehension about discontinuing the monitor in the future and in one case, a fear that the tightness of the monitor belt might interfere with growth of the infant's chest.

Concerns of Mothers Attributing Slight Risk to SIDS-Sibling

Fewer mothers attributing slight risk to their SIDS-siblings expressed concerns about infant behavior and care. However, this group had more concerns about their life circumstances, including: Unemployment; financial problems; father absence from the home; illness of a family member; and behavioral problems with older children. One family experienced disappointment over the sex of the subsequent infant and was the only participant with a SIDS-sibling of a different sex than the previous infant. More mothers in the slight risk category felt solely responsible for the care of the SIDS-sibling on the monitor.

Concerns Common to Both Risk Groups

Concerns which were common to the total group included: Changes in infants' sleeping patterns; respiratory infections; finding babysitters; feeling physically isolated; and feeling emotionally isolated.

Factors Contributing to Maternal Concerns

During discussions about home monitoring and care of the SIDS-siblings, it became apparent that several factors contributed to maternal concerns and the resulting interventions mothers created for the care of the SIDS-sibling. Some interventions were physical in nature, such as not disrupting the infant's routines; whereas some interventions seemed more emotional in nature, such as increased worry or focusing attention on the possibility of SIDS or monitor alarms. The following section elaborates on the factors that contributed to maternal concerns and the resulting care-giving interventions mothers created for the care of their SIDS-siblings.

Memories of the SIDS Death

Memories about the events surrounding the death of the previous infant influenced ideas about what was a safe activity for the SIDS-sibling. The following comments from three mothers indicate the kind of interventions created on the basis of mothers' memories:

> I will not take my baby to other people's homes because my first baby died in someone elses house. I just don't want to go through that again.
>
> I won't interrupt my baby's sleep for anybody or anything. My baby died following an airplane trip home from visiting my parents.
>
> I worry more about apnea after a shopping trip. My baby died after an all day shopping trip with my mother. I always put her on the monitor as soon as we get home and I check her more frequently.

It is interesting to note that comments imply an understanding by the mother of the reason for her intervention. Some mothers commented on the illogical nature of their fears about these activities. Although the connections made between certain activities and SIDS were sometimes recognized as fantasy, these connections were acted upon by mothers as though they represented empirical facts.

Memories About the Previous Infant

Five mothers compared physical and personality attributes of the subsequent SIDS-sibling with the previous infant. Differences between the SIDS-sibling and previous infant were interpreted as an indication of the greater likelihood of survival as indicated by the following comments:

> I trust this baby more because he is more responsive and hyper than my baby that died. I just trusted more that he would be okay. My last baby, I just couldn't put him down. He wanted to be with me all the time.
>
> My first baby was lazy and didn't respond to me. This baby is so hyper and active. She is full term and doesn't have any breathing problems like "X". My first baby was never very well.
>
> This baby's breathing is clearer. I can see his body move or movement of his head when he breathes. With "X", I just couldn't tell if he was breathing. His color was always pale. I don't think he was a healthy baby. This baby's color is much pinker.
>
> I feel better about this baby than my baby that died because she is so active. She smiles at me and gets excited when I talk to her. My last baby didn't do any of those things.
>
> I worry more about this baby than my first SIDS-sibling. He is sleepier and not as alert.

As indicated by these comments, mothers equated an alert, responsive and active infant with life and health. The presence of these qualities provided mothers with reassurance and hope that the SIDS-sibling would survive.

The SIDS-Sibling's Behaviour

Five mothers said they worried more about SIDS if their infants' sleeping patterns changed. For some, the nature of the worry coincided with events surrounding the SIDS death. One mother worried if her infant got less sleep than usual and felt that SIDS occurred shortly after the infant fell asleep, as she had experienced with her previous infant. This mother said she worried less about the infant after his first hour of sleep. Two mothers worried if changes occurred in the number of hours or frequency of sleep. Two mothers checked their infants more frequently if a period of sleep lasted longer than usual. These words of one mother demonstrate the influence of sleep changes on her fears about SIDS:

> If he had slept longer than usual then I watched more closely and felt monitor alarms were more likely to be apnea/bradycardia alarms than a machine problem; whereas if he had been asleep for a short time then I felt alarms would more likely be loose lead alarms.

For one mother, changes in the infant's sleep activity patterns was particularly distressing. Her distress and the influence of memories concerning life with the previous infant are reflected in this comment.

> I was feeling okay about how things were going until he started to wake up and want to eat during the night. That's exactly what my last baby did before he died. I don't want to lose this baby.

It is apparent from their comments that mothers observed connections between their life events and the SIDS death of the previous infant. These connections were most obvious when mothers discussed situations or SIDS-sibling behaviors that reminded them of life with the previous infant. Similarity of events or behaviors is not a reliable index of contingency or cause-effect relationships, yet mothers relied on the qualities of resemblance or similarity and difference to determine if activities or infant behaviors posed a threat to their infant's life and health. Using similarity of events to determine the outcome is an inductive logical process but is often mistaken in its conclusions. Consequently, the concerns and caregiving interventions mothers created on the basis of memories about the previous infant took on the quality of myths or fantasies. However, to label these thoughts as fantasies and myths on the basis of their erroneous conclusions, is not to deny the probability that such thoughts have an important protective function.

Monitor Alarms

Although mothers seemed aware that absence of monitor alarms did not preclude a SIDS event, they felt reassured when their infants did not have monitor alarms. One mother remarked:

> My baby has not had any monitor alarms, not even a loose lead alarm, even though I set the time adjustment on the monitor for 10 seconds rather than the recommended 15 seconds.

Another mother who was discussing changes in her infant's behavior remarked, "But there haven't been any monitor alarms". In another case, fear about apnea was displaced onto a household pet. The mother said she found herself shaking her dog on several occasions because she thought the animal had stopped breathing.

There was only one infant in this study who experienced apnea requiring vigorous stimulation during the data collection period. Therefore, it is difficult to determine the contribution of apnea episodes to mothers' concerns about SIDS and the care of the infant. In the one case, the slight risk attributed to the infant did not change following the apnea episode. However, for at least three weeks following the apnea episode, the mother's anxiety level increased from slight to large and the monitor, which had been used only at night, was now used during the day as well. This mother also experienced more difficulty leaving the infant with a babysitter following the apnea episode. A question arises as to whether maternal concerns and caregiving interventions based on an actual episode of apnea differ from those based on a fear that apnea might occur.

Responses to Other People

The responses of friends and relatives sometimes reinforced the idea that everything was not "okay" with the SIDS-sibling. Mothers felt they were avoided because of others' fears of the baby dying. The physical and emotional isolation mothers experienced as a result of people's responses are indicated by these comments:

> I never see my nieces and nephews anymore. They just don't visit - I think because their parents are afraid the baby will die while they are here.
>
> People avoided us like they think the baby has a social disease or something.
>
> I know there were arguments among my friends about whether they should have a baby shower for me. They did, but only eight people showed up. I think they are afraid the baby will die when they're here.

Explaining the reason for using a cardiorespiratory monitor with an essentially healthy infant was a difficult task. Most mothers felt, that in spite of explanations, friends often saw the monitor as an indication the baby was ill and in a life-threatening situation. The perception of mothers that people avoided the SIDS-sibling was further intensified with the difficulty of finding someone who would learn to care for the infant in their absence. One mother stated:

> I don't understand why people won't babysit. They look after other people's babies and they could die of SIDS too.

Another participant commented:

> I had two girls who were qualified to babysit. They came once but wouldn't come back. They always had an excuse.

For one family, difficulty finding babysitters was one of the reasons the monitor was discontinued. The importance of having a reliable trusted babysitter was manifested in this mother's comment:

> Having a babysitter who you can trust is the most help if you have to leave the baby. I think if my babysitter moved I would almost have to move with her.

When people avoid contact with the SIDS-sibling, the implied message is that the SIDS-sibling is at more risk than other babies. These messages, even if infrequent, may render it more difficult for mothers to maintain a realistic perspective on the chances of their infant having a SIDS event.

Not only did mothers feel the risk of SIDS to their infants was overestimated by others but comments indicate feelings that others underestimated the risk of SIDS to all infants:

> I just get appalled at what some mothers do, like leave their baby unchecked for hours, cover up the baby's face or use those snugglies where they don't know if movements are the baby's breathing or theirs.
>
> I get really angry when people try to tell me everything is okay because I have a healthy baby. I know having a healthy baby doesn't mean anything.
>
> I get really angry when my relatives tell me that SIDS could never happen to their babies.

Mothers felt emotionally isolated with their fears about SIDS, particularly when comments from others indicated a lack of understanding of the unexpected nature of SIDS.

Five mothers felt the constant supervision of the SIDS-sibling was misunderstood. Mothers were labelled by friends and relatives as "overprotective", "smothering", or "hypochondriacs". Sometimes, interventions aroused questions from friends about the infant's health or the necessity of the mother's actions:

> When I am visiting other people they keep asking why I check the baby so much. It's hard to make people understand that I'm not crazy.
>
> I don't like to take my baby to other peoples houses because they don't understand that he has to be watched closely. They would pressure me to leave him in another room and then ask, Why not? Why can't you do that? What's wrong with him?

Perhaps a difficult task for friends and relatives is to distinguish between maternal interventions with the SIDS-sibling and the actual risk to the SIDS-sibling's life. One participant who felt increased support from family and friends, attributed this in part to her ability to express feelings, fears and anxieties and to explain her need to closely supervise and use a monitor with her essentially healthy infant.

Empirical Knowledge About SIDS

Mothers created interventions for SIDS-siblings based on their knowledge of Sudden Infant Death Syndrome. For example, one mother planned her pregnancy so the SIDS-sibling would reach the critical age for SIDS, during the season SIDS deaths were lowest in Alberta, the previous year. Information about the use of water beds for apneic premature infants influenced a mother's decision to use equipment with her infant that moved, such as a water-filled crib mattress and an infant seat with rockers.

Knowledge about SIDS also influenced the points in time mothers perceived as most stressful. One mother whose previous infant died at 5 1/2 months, said:

> I think I will worry most around 3 months of age because that's when I know most SIDS deaths happen.

Regardless of whether previous infants died at 5 1/2 months or 5 1/2 weeks, mothers consistently said that 2 to 4 months was the most stressful period of home monitoring. This stressful point was identified by two mothers from a retrospective point of view, two presently in the 2 to 4 month period and two mothers anticipating this age period with the infant. If the previous infant died between 2 to 4 months of age, this anniversary date was an additionally stressful time.

When infants had colds, mothers said they worred more about SIDS. Again, a sequence of events with the SIDS-sibling similar to events with the previous infant was very stressful. Such was the case with one participant when her SIDS-sibling developed a cold at exactly the same age as her previous infant prior to his death.

All mothers said they worried or thought they would worry less after the infant turned 6 to 8 months of age because SIDS occurred less frequently after this period of infancy. Mothers said they would not "rest easily" until the infant turned one year and in some instances 3 years of age.

Discontinuing the Monitor

Three mothers had experienced discontinuing the monitor with the study infant or a previous SIDS-sibling and three mothers were anticipating this period of time. Although mothers could remember the exact date and age of the infant when home monitoring was initiated, no one could remember the infant age or date the monitor was discontinued. Comments revealed feelings of guilt and fear about discontinuing the monitor:

> We wanted to use the monitor for one year. I don't remember the date we discontinued the monitor but I think she was about 9 months old. This is about one month longer than babies usually stay on the monitor.
>
> I don't remember how old he was when we stopped using the monitor. I think it was about 7 months. We wanted to use it for one year. We did everything we could to keep him from pulling the plug. We even made mittens for his hands.
>
> I will use the monitor for one year and I have already discussed this with the doctor.
>
> I feel anxious when I think about discontinuing the monitor.

All mothers said they would use the monitor for one year. In some cases, interventions to keep the infant attached to the monitor such as mittens, restraining and placement of monitor wires were created in anticipation of difficulties. Comments indicate the extremely painful nature of making the decision to discontinue the monitor.

Two mothers who had discontinued the monitor said termination was easier when they learned to trust the baby and realized they, not the infant, needed the monitor. It seems that implicit in the comment of "trusting the baby" is a conscious decision to now give the choice of breathing or not breathing to the infant. Perhaps learning to trust the infant to breathe unassisted, is a positive step in the mother's awareness and knowledge of her SIDS-sibling's capabilities.

The Monitor

The monitor did not appear to contribute to mothers' concerns but provided information about the infant that was reassuring and comforting. Generally, this was true whether infants did or did not have apnea/bradycardia episodes. Mothers said they experienced home monitoring as easier than expected. Most attributed this to few alarms or having only false alarms.

Participants expressed a variety of ways in which the use of an apnea monitor was helpful. Two mothers said, without the monitor, they would not be able to check their babies after a period of sleep. Even with the monitor, these mothers said they checked for breathing prior to looking at the infant's face. One mother wanted to know the time of a SIDS event, should one occur. Most families wanted an opportunity to try and revive their infant should a life-threatening episode of apnea occur. All families found the monitor helped them relax with their infants and sleep better at night. Five mothers said they would use the monitor again and one mother was uncertain. Generally, mothers perceived the monitor as their "eyes and ears" when they needed to sleep or required time away from the infant.

Summary of Results

Three of the six participants placed their SIDS-siblings in a large risk category and three attributed slight risk to their infants. Mean scores were higher for dyads in the large risk category on the following variables: Maternal age, infant age, the number of months since the SIDS death, apnea/bradycardia episodes, the number of months between the SIDS death and birth of the subsequent infant, hours per day of monitor use and the Total HOME Inventory and NCAFS (interaction) Scores. Mann-Whitney U tests, one-tailed for small sample sizes, revealed significant mean differences on: The number of months since the SIDS event, the Total HOME score and the Total NCAFS score. Least significant mean score differences between the large and slight risk dyads were obtained on infant age and apnea/bradycardia episodes. All mothers attributing large risk to SIDS-siblings had experienced the

SIDS death of their first infant; whereas two mothers attributing slight risk to the SIDS-sibling had preschool children.

Further analyses, using Mann-Whitney U tests, revealed significant differences in favor of dyads in the large risk category on the following NCAF Scales: Mother's Social-Emotional Growth Fostering Behavior, the Total Child Score, and the Total Parent Score and Parent Verbalization. Significant differences on HOME Inventory scores between risk groups were obtained for: Emotional and Verbal Responsivity of the Mother, Provision of Appropriate Play Materials and Maternal Involvement.

It is possible that the cumulative effect of some demographic variables may have influenced the more favorable HOME Inventory and NCAFS scores obtained by mother-SIDS sibling dyads in the large risk category. These demographic variables included older maternal age, more maternal education, no surviving children in the family prior to the SIDS death, maleness of the SIDS-sibling and the slightly older age of SIDS-siblings at the time of data collection. Differences according to infant age were more apparent within the groups based on risk than for the total group suggesting that factors other than infant age also contributed to significant differences between dyads placing the infant in a large versus slight risk category.

More mothers attributing large risk to the SIDS-sibling expressed concerns about infant care, infant behaviors and monitor management. More mothers attributing slight risk to SIDS-siblings expressed concerns about their life circumstances. Lack of social support, and more apprehension about SIDS when infants changed their sleeping patterns were common concerns of participants.

Factors which contribute to mothers' concerns about the infant and stressful points during the home monitoring experience, included: Memories of the SIDS event; memories of the previous infant; the infant's behavior; monitor alarms; and the empirical knowledge mothers had acquired about SIDS. Mothers used similarity, likeness, resembalance as well as differences between experiences with the previous infant and SIDS-sibling to create interventions for the safe care of the SIDS-sibling. Interventions were both physical and emotional. For example, mothers not only used memories to decide what was or was not a safe activity for the SIDS-sibling but also to decide when to worry. Mothers perceptions of others' responses to the SIDS-sibling and monitor reinforced the idea of the SIDS-sibling's vulnerability. The monitor did not contribute to mothers' concerns but seemed to be a source of comfort and reassurance.

CHAPTER 5

Discussion, Conclusions, Limitations Implications and Recommendations

The objective of this study is to describe the characteristics of interaction and the home environment with mother-SIDS sibling dyads using the home monitoring intervention. In this section, major results are discussed and compared to results of previous research. Limitations of the study, implications for nursing and recommendations for future research are outlined.

Discussion of Results

Discussion of the results focuses on maternal attribution of risk to the SIDS-sibling, and the characteristics of mother-infant interaction and the quality of the SIDS-sibling's home environment. Factors which may account for variations in measurements among mother-SIDS sibling dyads and between the study and normal samples are examined in relation to other research.

Maternal Attribution of Risk to the SIDS-Sibling

Three of the six mothers in this study attributed large risk and three slight risk to their SIDS-siblings. This section examines some factors which may account for variations in the degree of risk mothers attributed to infants. These factors include: Reactions to the loss or threatened loss of an infant; the time interval since the SIDS event; previous experience mothering a surviving child; the apnea monitor; and the sex of the SIDS-sibling.

Reactions to the Loss or Threatened Loss of the Infant

Maternal attribution of risk to SIDS-siblings, as well as the concerns mothers expressed about their SIDS-siblings' behavior was reminiscent of the grieving process. Perceiving the subsequent infant as at risk may be a reaction to the loss of a previous infant due to SIDS. Similar grief reactions in parents who perceived their infants as less viable at birth have been reported.

Reseachers, in a followup study of 90 children at 5 years who had RH Incompatibility at birth, found mothers retained little of the realistic information given to them at birth. Over time, mothers perceived children as less viable and more likely to die, regardless of the actual heatlh status of the child (Rose, Thomas, Boggs, Alderstein, Trigos, Rigg, & Crowther, 1960).

Rose (1961) reported a variety of factors, including the death of a previous infant, that contributed to less adaptive mother-infant relationships. Grief reactions, in anticipation of the death of their essentially healthy infants, led mothers to perceive behavioral or physical changes in infants as life threatening, despite reassurances. Mothers sometimes failed to provide adequate stimulation or provided stimulation inappropriately.

These descriptions are reminiscent of three mothers in this study who attributed large risk to their SIDS-siblings. Maternal concerns about the SIDS-siblings centered around behavioral changes such as sleep patterns and activity levels. Behavioral changes in the SIDS-siblings were particularly distressing to mothers when they aroused memories of the previous infant's behavior before the SIDS event. Difficulties separating from the SIDS-sibling, including putting the infant down to sleep, were also reported by mothers attributing large risk to SIDS-siblings. In contrast, mothers attributing slight risk to SIDS-siblings reported no difficulties in these areas. These results are similar to a report by Green and Solnit (1964) that difficulty separating from children occurred when mothers perceived the child as vulnerable.

Time Interval Since the SIDS Event

The finding that mothers attributed a greater degree of risk to the SIDS-sibling when more time had elapsed since the SIDS death of the previous infant is surprising. If attribution of risk is in part a grief reaction, then it might be expected that less risk would be attributed to the infant with increased time since the SIDS event. These results raise a question about the length of the grieving process for mothers who have lost infants and the extent to which grief reoccurs with the birth of a subsequent infant, even years later.

A review of other research revealed little that would explain this result. Spinetta, Swarner and Sheposh (1981) measured the adaptation level of family members after the death of their child from cancer. No relationship was found between high or low adaptation levels and the time interval since the death. Researchers raised a concern about the extent to which memories of the child and his death interfered with daily functioning of family members and their commitment to the future, even two to three years after the death (p. 260).

Children who have experienced the death of a sibling were reported to obtain lower social-competency scores as the elapsed time since the death of the sibling increased. The researcher noted that the high number of internalizing behaviors reported for children supported a suspicion that many of these children were depressed (Davies, 1984). The decrease over time in the competencies of bereaved children suggests that time elapsed since death is an important variable to consider with research concerning the functioning of family members following a death.

Some mothers in this study said they became pregnant shortly after the SIDS event because waiting would have raised self-doubts about having another child. Perhaps as the time interval since the SIDS death increases, mothers become more doubtful about their parenting abilities. Further research should be done to determine the influence of time elapsed since the SIDS death on mother-SIDS sibling interaction.

Previous Experience Mothering a Surviving Child

An equally or perhaps more plausible explanation for differences in the amount of risk mothers attributed to SIDS-siblings may be the experience of mothering an infant who survived prior to the death of the infant from SIDS. Two mothers who attributed slight risk to their SIDS-siblings had older children; whereas none of the mothers who attributed large risk to their SIDS-siblings had surviving children prior to the SIDS death. Mothers with older children seemed aware of a broad range of infant behaviors and most interpreted changes in their SIDS-sibling's behavior as normal developmental sequences, rather than as life-threatening events.

Perhaps with a previous successful experience of child-rearing, mothers have less need to fantasize about the possible death of their infant and are more able to maintain a realistic perspective about the chance of SIDS. Reva Rubin (1984) reported less use of fantasy by multiparas than primiparas during the process of attaining the maternal role. Multiparas tended to use a frame of reference about their mothering in terms of what they did or what was done with the last baby.

It has been documented by several investigators that previous child care experience is associated with fewer concerns about infant behavior and care: Second-time mothers appeared to be more concerned about integrating the new baby into the family (Bull, 1981; Filmore & Taylor, 1976; Gruis, 1977; Moss, 1981).

The Apnea Monitor

It is interesting to note that infants in this study, with and without reported episodes of apnea, were placed in both slight and large risk categories; whereas, Black and associates (1978), from a study on the impact of home monitoring on family life, said the monitor became the parents best indicator of the severity of risk to the infant.

In the study by Black and associates (1978) most parents had already discontinued the monitor, whereas four of the six SIDS-siblings in this study were still using the apnea monitor at the time of data collection. Maternal perception of infant risk may be based on the monitor when viewing the situation from a retrospective point of view. In this study, of the two SIDS-siblings who were no longer using an apnea monitor, one was placed in a slight risk and one in a large risk category. The mother attributing slight risk to her SIDS-sibling at age two to four months, in retrospect, perceived that her infant never really needed the monitor. In contrast, the mother attributing large risk to her infant at two to four months, in retrospect, perceived that her baby had several episodes of life-threatening apnea or bradycardia while using the monitor. Of the four mothers using the apnea monitor during data collection, two attributed slight risk and two large risk to their SIDS-siblings. It seems that these mothers were influenced by factors other than the monitor alarms as an indicator of the severity of risk. Results of this study suggest maternal perception of infant risk was influenced as much by the SIDS death and the threatened loss of the subsequent infant as by the monitor alarms.

Sex of the SIDS-Sibling

Three SIDS-siblings placed in the large risk category were male, while three placed in the slight risk category were female. In the past, more SIDS deaths have been reported for males than for females (Kelly & Shannon, 1982).

In all but one case in this study, the sex of the subsequent infant was the same as the infant who died. In one case, the mother expressed more worry about SIDS because her infant was male. Other researchers have reported that mothers have more concerns about male than female infants, particularly if the infant was a first-born male (Moss, 1981; Sumner & Fritch, 1977). Such research findings raise the question of infant sex as an influencing factor in maternal perceptions of the infants' vulnerability.

Variations Among Mother-SIDS Sibling Dyads on Interaction and the Infant's Home Environment

Data analysis revealed two separate profiles for the six mother-SIDS siblings on characteristics of mother-infant interaction and the infant's home environment. This section examines some factors which may have contributed to these differences, including: Participants' life circumstances; time elapsed since the SIDS death; demographic characteristics; and maternal attribution of risk to the SIDS-sibling.

Participants' Life Circumstances

One group of three mother-SIDS siblings demonstrated a less animated style of interaction with less verbal and tactile stimulation and fewer mutual exchanges of a purely social nature. Infants, as well, were less responsive and displayed a smaller repertoire of behaviors. HOME data provided evidence of less verbal responsiveness and involvement with the infant during the course of daily activities. A variety of age-appropriate play materials were not as accessible to the infants in these three dyads.

The results show a group of low energy, less involved mothers. Care tended to be instrumental and task oriented, giving the appearance of less enjoyment between mother and baby. The lack of involvement and low energy is understandable as these mothers were overwhelmed with other problems such as ill family members and financial difficulties. As well, mothers reported a lack of emotional and physical support from friends and families.

Time and energy are limited resources. Reports by other researchers support the idea that less favorable life circumstances decrease the amount of energy and attention available for mothering. Unger (as cited in Unger & Powell, 1979) found that mothers who experienced high levels of stress were less likely to be involved with their infants as measured by the HOME Inventory. Mothers were more likely to be involved with their infants if they had emotional and physical support from friends and relatives.

Barnard and Eyres (1979) reported mothers with high life-change scores during pregnancy and low psychosocial assets including negative feelings about pregnancy, a lack of emotional and physical support and more disruptions in plans showed less positive maternal behaviors by the time their babies reached one year of age. These mothers gave more negative messages, were more restrictive, were less involved with their infants and showed less adaptive behaviors during feeding (pp. 109-110).

Time Elapsed Since the SIDS Death of the Previous Infant

It is also possible that dyads with less favorable interactions and home environments were affected by the shorter period of time since the occurrence of the SIDS death. Two mothers in this group were pregnant less than five months after the death of the previous infant. It may be that mothers' low energy level and low involvement reflect some depression and unresolved grief. Rowe and his associates (1978) reported the only factors associated with prolonged grieving reactions in mothers who experienced a perinatal death occurred with mothers who had a surviving twin or became pregnant less than five months after the death. No differences in grief reactions were found for age, economic status, cause of death, presence of older children or the interval between the infants' death and the interview.

Difficulties conceiving, based on emotional factors, have been reported to occur subsequent to the death of an infant from SIDS. Researchers suggest that unresolved grief, self-blame, guilt and misgivings about abilities for parenthood place at risk, mothers who have lost a child to SIDS. As a result, the environment for the subsequent newborn may not be as healthy (Mandell & Wolfe, 1975). Researchers also report that it took on the average of 16 months after a SIDS death for family members to regain the level of personal happiness experienced prior to the death (DeFrain & Ernst, 1978).

As presented in Table 5, the more months that had elapsed since the occurrence of the SIDS death, the more favorable were the HOME and NCAFS scores for the dyads in this study. Of the three participants who demonstrated as much or more verbal responsivity and involvement with SIDS-siblings as occurred with normal dyads, two mothers had given birth to subsequent infants 30 or more months following the SIDS event. In one case the infant was a second SIDS -sibling. These dyads also exhibited more adaptive behaviors during feeding than dyads whose infants were born 10 to 16 months following the SIDS event. The results of this study support the idea that the psychological milieu for the developing mother-infant relationship may be healthier as the time elapsed since the SIDS death increases.

It is interesting to note that as the time interval since the SIDS death increased, mothers not only exhibited more favorable interactive behaviours but also attributed a greater degree of risk to their SIDS-siblings than those mothers who experienced the SIDS death more recently. These findings appear inconsistent suggesting further research is necessary to determine the nature of the relationship between time elapsed since the SIDS death, the mother's perceptions of risk to the SIDS-sibling, and the quality of the mother-SIDS sibling's interactions.

Demographic Characteristics

Demographic characteristics of mothers and SIDS-siblings may also help explain the reason that three of the six mother-SIDS sibling dyads exhibited more favorable mother-infant interaction. Characteristics of dyads obtaining more favorable scores on measures of interaction included: Mothers tended to be older and have slightly more education; the infanct who died of SIDS was a first-born male; SIDS-siblings were all male and slightly older at the time of data collection that SIDS-siblings in dyads obtaining less favorable scores on measures of interaction.

The cumulative effect of older mothers and infants and more maternal education, in combination with the longer time interval since the SIDS death of the previous infant, may have increased the likelihood of these three mother-SIDS sibling dyads obtaining higher scores. Other researchers have reported lower scores on measures of home stimulation and maternal behaviour during feeding for mothers who were under 19 years and had 12 or less years of education (Barnard & Eyres, 1979). Infants who are more developmentally mature are also reported to obtain higher HOME Inventory and NCAFS scores (Barnard, 1978a; Caldwell & Bradley, 1984).

The tendency of dyads with older infants to obtain higher scores on measures of interaction may, in part, be due to maternal knowledge of the age at which developmental milestones occur. Based on a study of the relationship between mothers' developmental expectations and infant development, researchers found the later the age at which mothers expected babies to see, hear, be aware of surroundings and to be ready for teaching and verbal exchanges, the lower were the Total HOME Inventory scores at 4, 8, and 12 months of age. Mothers with later developmental expectations for their babies had less education, lower family incomes and less social support during pregnancy (Snyder, Eyres, & Barnard, 1979).

Although mothers' developmental expectations of SIDS-siblings were not measured in this research study, it is interesting to note that in two of the three dyads obtaining lower HOME Inventory and NCAFS scores, mothers felt their SIDS-siblings were too young to be given toys or to play. It seems likely that developmental expectations will influence mother-infant interaction and would be an important variable to measure in future studies.

Maternal Attribution of Risk to the SIDS-Sibling

Mothers who attributed large risk to their SIDS-siblings and expressed more concerns about their infants' behavior, exhibited more adpative behaviors during feeding interactions and more involvement with their babies. Some researchers suggest that anxiety and worry about the infant may result in a less positive mother-infant relationship (Kennedy, 1973; Southall, 1983). However, it is possible that in the case of some mothers in this study, concerns about the infant facilitated adaptive mother-infant interactions.

Filmore and Taylor (1976), based on research of primigravidas' infant-care concerns, suggested that maternal anxiety about the infant has an interest and worry component. The researchers proposed that when infants have special problems, the anxiety component of concerns is unlikely to diminish, while the interest component of concerns ought to grow and develop along with the child's growth and development. Authors stated that in some cases, a low level of anxiety in the mother's concerns may be unhealthy and show a deteriorating mother-child relationship (p. 24).

All mothers, regardless of the degree of risk attributed to the SIDS-sibling, worried about the possibility of SIDS. This worry resulted in much maternal instrumental care, if not verbal or tactile social exchanges. It seems reasonable that mothers of SIDS-siblings will worry to some degree about the possibility of a SIDS event. The fact that only 2 per 1000 infants die of SIDS may be of little comfort to the mother of a SIDS-sibling.

There is evidence in this study, that for some mothers, the anxiety about SIDS carried over into daily activities with the infant. More mothers attributing large risk to infants had difficulty enjoying changes in their infants' development. In some cases, maternal concerns resulted in fewer mother-infant outings and difficulty separating from the infant. In one case, the mother slept in her infant's room so she could change his position if he aroused during the night. In another case, a mother who worried about the sleepiness of her infant, exhibited stimulating behaviors during feeding which were intrusive and inappropriate to the infant's state. The HOME Inventory and NCAF Scale measure only understimulation. However, there are some indications that overstimulation and inappropriate stimulation outside of the feeding context should also be measured in future studies of mother-SIDS sibling interaction.

Differences Between the Study and Normal Samples on Interaction and the Infant's Home Environment

In comparison to the normal sample, mother-SIDS sibling dyads were inclined to be less sensitive to infant cues and more restrictive. The quality of social-emotional support and cognitive stimulation was less favorable for mother-SIDS siblings than for a group of normal dyads. In this section, specific differences between the study and normal samples are examined and possible explanations are suggested.

Sensitivity to Infant Cues

In comparison to a normal sample of mother-infant dyads, mothers of SIDS-siblings were significantly less sensitive to their infants' cues indicating hunger, satiation and a readiness to interact or disengage. This was particularly so for the three mother-SIDS sibling dyads who expressed concerns about their life circumstances such as unemployment and financial difficulties. Interactions between life stress and aspects of the mother-infant relationship have been reported by researchers. Crnic, Greenberg, Ragozin, Robinson and Basham (1983) measured the effect of stress and social support on mother-infant interaction, using the same conceptual categories as the NCAF Scale but during a teaching, rather than a feeding situation. The only subscale significantly related to stress was the Mother's Sensitivity to Infant Cues. Mothers reporting greater life stress were rated as less sensitive to their infant's behavior. When other life stresses are superimposed on the care of a new infant, it is understandable that energy available for attending to infant cues will be less.

Other researchers have reported that most new mothers initially experience a certain degree of uncertainty about the infant's cues and their meaning (Shereshefsky & Yarrow, 1973). Sander (1976) identified several issues in the early mother-child interaction from a longitudinal exploratory study of 22 mother-child dyads from birth to three years of age. A central issue in the first 2 to 3 months of life concerned the appropriateness of maternal responses to the cues the baby gave of his state and needs (p. 130). In this early period of infancy, a mother is attempting to surmount the anxieties of providing an environment adequate to sustain the life of her infant. Once the mother has accomplished this task, the dyad becomes more involved in the task of developing reciprocal sequences of interchange.

This information raises another possible explanation for the less favorable scores of the study sample on Sensitivity to Cues. It seems plausible that infants who require special care may render more difficult the maternal task of identifying and responding appropriately to infant behaviors. Results of studies on mothers' concerns about infants with special problems such as heart disease, indicated that learning to differentiate normal behavior and behavior associated with illness posed a special problem for mothers (Pinelli, 1981; D'Antonio, 1976). Although SIDS-siblings are not ill, mothers in this study tended to search for infant behaviors such as breathing, activity and regularity of sleep patterns that would confirm the SIDS-siblings' health and well-being. When maternal attention is focused on infant's breathing and physical states, there may be less likelihood of attending and responding to the social cues of the infant's behavior.

Comments about concerns related to infant behavior and care also revealed a tendency for mothers to build caregiving interventions on the basis of memories of the previous infant and information about SIDS. While these interventions may provide a mother with some sense of control over the life of her baby, mothers are also acquiring knowledge about the infant. Some mothers in the sample acted on beliefs that travel, developmental changes in sleeping and eating patterns or less infant responsiveness forewarned a possible SIDS event. These mothers may have fewer opportunities to learn about the infant's responses, the meaning of those responses under a variety of circumstances and the infant's ability to adapt to change and different environments. According to Sander (1976), the dimensions of an infant's organization can remain unknown to the mother for a considerable time if she is not perceptive of the cues supplied in his behavioral feedback to her (p. 131).

The Quality of Stimulation in the SIDS-Siblings' Home Environment

All mothers of SIDS-siblings provided much instrumental care during the course of daily activities. SIDS-siblings were kept in constant visual and auditory range. Mothers were observed to frequently check infants' breathing by observing the face or placing their hand on the infants' chest.

It seemed likely that this type of proximity would increase the frequency of some developmentally positive interchanges between mother and SIDS-sibling during the course of daily activities. In general, this was not the case in comparison to the normal group as measured by the HOME Inventory. Perhaps when mothers are attuned to the physical well-being of the infant, stimulation through auditory and visual exchanges becomes less of a priority.

Of particular interest is the significant difference in favor of the normal group on the HOME subscale, Avoidance of Restriction and Punishment. Hayes (1980) reported Avoidance of Restriction and Punishment as the HOME subscale most predictive of later cognitive development in a group of premature infants. Perhaps this conceptual category is identifying a tendency of mothers to be more restrictive when they perceive their infants' life is at risk or have infants whose physical status requires more than usual baby care.

The Home Monitoring Experience

Mothers' reports about the home monitoring experience were similar to reports of other researchers, particularly with respect to aspects of social support and the apnea monitor.

Social Support

Five of the six mothers expressed a concern about locating reliable babysitters. Difficulty finding babysitters was reported in most studies concerning the impact of home monitoring (Black et al., 1978; Cain et al., 1980; Wasserman, 1984), as well as studies looking at the impact on family life, of caring for a chronically-ill child (Aradine, 1980; Willis, 1983). Similar to a report by White and Dawson (1981) in a study of families caring for at-risk infants, it seemed that some mothers of SIDS-siblings in this study, not only had trouble finding a reliable babysitter, but were also very reluctant to leave infants with some one else, even if they were trained in monitor management. In some instances, mothers of SIDS-siblings were hesitant to leave the infant with the father.

Reva Rubin (1984) notes that for the new mother, a babysitter is a surrogate who values the infant, knows the infant and can watch with eyes and ears for what does not occur, such as breathing, as well as what does occur (p. 125). It is understandable that mothers of SIDS-siblings will have more difficulty trusting another person, no matter how reliable, to sustain the life of their baby.

Regardless of the degree of risk attributed to SIDS-siblings, mothers reported inadequate physical and emotional support. Researchers who looked at the impact of caring for a child with special needs, also reported parental feelings of emotional and social isolation. White and Dawson (1981) reported that families with infants requiring special care got out less frequently as a couple, felt less close as a family and had the least help with the infant.

Mardiros (1982) used an ethnographic approach to explore the experience of 12 mothers caring for physically handicapped children. Although this was a small sample, the lack of consistent support from friends, spouses and professionals was a noticeable feature of the sources of stress expressed by mothers.

Wasserman (1984) conducted a longitudinal study with families using the home monitoring intervention. Similar to the reports of mothers in this study, subjects in Wasserman's study reported feelings of isolation related to the reluctance of family and friends to visit because of fears that "something might happen" while they were present.

Researchers report that some situations such as pregnancy and parenthood evoke a great deal of spontaneous support, while other situations involving grief work such as the death of an infant or the threat of death evoke much less support (Helmrath et al., 1978; Quint, 1963). There is also evidence to suggest that support in anticipation of a stressful event is more difficult to provide than support during or following a stressful event (Norbeck, 1981).

Adaptive maternal behavior is influenced favorably by the mother's perceptions of her social support and others' responses to her in her role (Mercer, 1981; Russell, 1974). Barnard (1981a) reported that maternal involvement with the infant was correlated with the mother's report of whether her needs for emotional support were met.

Doubts about the ability to care for a baby on a monitor have been reported (Black et al., 1978; Wasserman, 1984). Results of this study indicate that mother's perceptions of others' responses to herself, her SIDS-sibling and the home monitoring intervention may be a factor influencing the experience of mothering a SIDS-sibling on an apnea monitor. Mothers may need assistance to find ways of approaching intolerant or well-meaning but misinformed friends and relatives. As well, a question arises as to the impact of a SIDS death on relatives and friends.

The Apnea Montior

Participants in this study felt the monitor helped them relax, sleep at night and feel more confortable with their SIDS-siblings. At the same time, it was apparent that the relationship with the monitor was an ambivalent one. Mothers were thankful for the monitor but wished they didn't need it and at the same time were apprehensive about giving it up. While the monitor is a source of comfort, it is also a constant reminder of the possibility of SIDS. A question arises concerning the extent to which the presence of the monitor aggravates the reoccurrence of grief with the birth of the subsequent SIDS-sibling.

The painful nature of the decision and process of discontinuing the monitor was evident from the reports of mothers in this study and is supported by statements from others (Babkirk, 1981). Wasserman (1984) reported that pre-existing problems worsened in families after the monitor was discontinued, resulting in a high divorce rate (43%). Families who showed poor self-confidence were particularly vulnerable to difficulties discontinuing the monitor.

Unlike reports from other researchers (Black et al., 1978; Cain et al., 1980), mothers in this sample reported few problems managing the technical aspects of home monitoring. This may, in part, be due to more recent, better home monitoring equipment and the availability of a home monitoring program. Few participants reported interference in daily activities such as outings or household activities. When difficulties were reported in these areas, they arose from fears about what was a safe activity for a SIDS-sibling, rather than from the technical aspects of managing an infant on an apnea monitor. The fact that SIDS-siblings in this study were not usually monitored during waking hours, may account for mothers' reports about little interference in usual daily activities. Mother-infant interaction and the stimulation available to the SIDS-sibling were not directly influenced by the monitor. Mother-infant activities were not curtailed because the infant was on a monitor, but appeared to have more to do with fears about SIDS.

In summary, while the presence of the monitor was a source of comfort to mothers and generally did not interfere with aspects of daily living or mother-infant activities, the monitor is also a constant reminder of the possibility of SIDS. This reminder may contribute to ongoing grief reactions. As well, others' negative responses may influence maternal confidence and hence the mother-infant relationship. Further research is necessary to determine the individual contributions of the apnea monitor, the loss of an infant from SIDS and social support to the experience of mothering a SIDS-sibling on an apnea monitor.

The Conceptual Model

The conceptual model used in this study, is the Child Health Assessment Interaction Model and is shown in Figure 1. The largest circle represents aspects of the environment. The smallest circle represents the characteristics of the SIDS-sibling, and the remaining circle represents the characteristics of the mother. The overlapping areas of the circles depict the interactive effects that may occur between the mother, the infant and the environment.

The results of this study confirm that characteristics of the mother, infant and environment influence one another. As can be seen by results presented in Table 11, low child and parent scores occurred together; whereas when parent scores were high, child scores were also high. These results support the idea that the NCAFS instrument measures interactive behavior based more on reciprocal adaptation than on consistent characteristics of the partners. Similarly, as presented in Table 5, dyads who were more adaptive during feeding interactions, also obtained more favorable assessments of the quality of stimulation available to the infant in the home environment. In particular, sources of animate stimulation were less available to SIDS-siblings in cases where interaction scores were less favorable.

Perhaps the most advantageous aspect of the Child Health Assessment Interaction Model is that it demands the researcher pay attention to the complexity of life circumstances, maternal beliefs and past experiences that will interact to determine the status of the mother-infant relationship at any point in time. Because of the complexity of factors that may influence interaction and the home environment, early assessments are not necessarily interchangeable with later assessments. However, at any stage of the infant's life, the presence of an organized predictable environment with involved responsive caregivers and reciprocal mother-infant behaviors, is an indication of the potential for the ongoing development of an adaptive mother-infant relationship.

Maternal attribution of risk to the SIDS-siblings and the interventions mothers created for the safe care of their infants could be explored in more depth with the use of the Health Belief Model. According to Champion (1984), with use of the Health Belief Model, behavior can be explained as resulting from an individual's views of the following four concepts:

1. Perceived susceptibility or the likelihood of experiencing a potentially harmful condition.

2. Perceived seriousness or how threatening the condition is to the person.
3. Perceived benefit of the effectiveness of specific behavior in reducing the threat of the condition.
4. Perceived barriers or the negative aspect of the anticipated behavior to reduce the threat.

These concepts may be potentially valuable in future studies for examining some of the perceptions and behaviors of mothers towards their SIDS-siblings.

In summary, the results of this study help to confirm the usefulness of the Child Health Assessment Interaction Model for explaining interactive influences on mother-infant interaction. The concepts used in the Health Belief Model may be useful for determining, more specifically, the influence of maternal perceptions of risk to the SIDS-sibling on maternal behavior and hence to mother-SIDS sibling relationship.

Conclusions

In general, mothers of SIDS-siblings in this study were as responsive to infant distress and provided as much social-emotional and cognitive stimulation during feedings, as mothers in the normal group. However, in comparison to normal dyads, mothers of SIDS-siblings were less sensitive to their infants' social cues during feeding, and provided environments that were more restrictive and less favorable in terms of the total social-emotional support and cognitive stimulation available to the infant. SIDS-siblings were generally as responsive as infants in normal dyads and exhibited a variety of communication signals and social cues for their ages.

On closer inspection of the SIDS-sibling sample, two profiles of mother-infant interaction and the stimulation in the home environment emerged. One group of three dyads were characterized by less favorable kinds and amounts of stimulation during the course of daily life and fewer social exchanges during feedings; while three remaining dyads were characterized by more maternal involvement and verbal and tactile exchanges both during and outside of the feeding situation.

It seems that in this sample, close proximity between mother and SIDS-sibling did not necessarily induce developmentally positive changes in the mother-infant interaction. Factors such as attribution of large risk and concerns about infant behavior, showed more consistent patterns in terms of maternal responsivity and involvement with the infant.

Several factors may have accounted for the more favorable interactions exhibited by three of the six mother-SIDS sibling dyads. These factors characterizing dyads obtaining more favorable scores included:

1. Mothers tended to be older with slightly more education.
2. Mothers were slightly more experienced with monitor management.
3. The SIDS death occurred with the first-born male.
4. SIDS-siblings were all male.
5. SIDS-siblings were slightly older at the time of data collection.
6. Mothers expressed fewer concerns relating to finances, employment and health of other family members.

7. More time had elapsed since the SIDS death of the previous infant.
8. Mothers attributed a greater degree of risk to the SIDS-siblings.

Maternal attribution of large risk to their SIDS-siblings, the tendency to view some infant sleep activity behaviours as potential life-threatening events, and interventions for the care of the SIDS-sibling created on the basis of memories about the SIDS death were reminiscent of the grieving process. It was expected that as the time interval since the SIDS death increased, mothers would attribute less risk to SIDS-siblings and exhibit more favorable interactions. Although mother-SIDS sibling dyads obtained more favorable interaction scores as the time elapsed since the SIDS death increased, these same dyads attributed a greater degree of risk to their SIDS-siblings than dyads who had experienced the SIDS death more recently.

Factors in which no patterns emerged in relation to attribution of risk or the separate profiles on interaction and the home environment, included:

1. Maternal confidence in the accuracy of monitors.
2. The severity and frequency of monitor alarms.
3. The hours per day of monitor use.
4. The proximity of anniversary dates to the time of data collection.

Many areas for further research concerning the impact of the SIDS death on mothers and subsequent infants have emerged from results. Some of these research areas include:

1. The length of the grieving process and the extent to which grief reoccurs following the birth of the subsequent SIDS-sibling.
2. The influence of time elapsed since the SIDS death on maternal

perceptions of the SIDS-sibling and confidence in parenting abilities.

3. The extent to which the use of the monitor aggravates or eases grief reactions which may occur in anticipation of the loss of the subsequent SIDS-sibling.

Mothers' descriptions of their lives, underscore the exhausting nature of the worries, fears, anxieties and isolation experienced with the loss of an infant and care of a subsequent SIDS-sibling on home monitoring. In general, it appears that factors related to the SIDS death contributed to the mother-SIDS sibling relationship as much or possibly more than the home monitoring experience. While the presence of the monitor is a reminder of the possibility of SIDS, it is also a source of comfort and reassurance to the mother. The individual contributions of the SIDS death, home monitoring and other factors to the mother-SIDS sibling relationship cannot be determined from this study. Further research is warranted.

Limitations

Caution in viewing the results of this study is advised. While the data presented may suggest factors such as maternal attribution of risk, grief reactions, time elapsed since the SIDS event and previous child care experience have affected the adaptive mother-SIDS sibling relationship, no cause-effect relationships can be assumed. Due to the small sample size, these results should not be generalized beyond the group to which they apply. In order to identify the individual contributions to the mother-infant relationship of home monitoring, loss of an infant, and other factors, a more controlled study would be necessary. The limitations of this study are as follows:

1. The sample was voluntary and small in size.
2. The validity and reliability of maternal attribution of risk and reports about aspects of home monitoring are limited by participants' insight and willingness to verbalize their thoughts, feelings and perceptions.
3. Knowledge of participation in a study may have influenced maternal behavior and responses.
4. The internal consistency of the HOME Inventory and NCAFS were not determined from the data obtained in this study.
5. Early HOME Inventory and NCAFS assessments are not necessarily interchangeable with later assessments.
6. The reciprocal quality of interaction during feeding does not necessarily reflect the quality of interaction in other contexts.

Nursing Implications

Generalizability of the study findings are limited because of the small, non-random sample. Implications must be considered in view of the limitations and, at this point, are not generalizable to a larger population.

Implications for Nursing Practice

The role of the nurse who is part of an organized support system for parents caring for infants on home monitoring, includes (McElroy, Ruginis, & Shaefer, 1979):

1. The provision of accurate information which is timely, sensitive

and relevant.

2. The provision of emotional support based on accurate understanding of the stresses that may be encountered under a variety of circumstances.
3. The strengthening of parents' problem-solving skills and coping strategies.
4. The mobilization of potential helpers who can respond sensitively and provide parents with temporary relief.
5. The early identification of families experiencing stress which is greater in degree and lasts longer than usual and who may require additional support and reassurance to manage difficulties (Favorito, Pernice, & Ruggiero, 1979).
6. Ongoing assessment and intervention aimed at promoting synchronous, reciprocal interactions, enjoyment of the infant and an environment conducive to normal infant development.

What is most significant about the area of parent-infant relationships, is that symptoms do not always exist as a stimulus to seek help. The nurse in the community or home monitoring program may follow the mother of the SIDS-sibling during pregnancy, throughout the home monitoring experience and for a period of time following termination of the intervention. Moreover, she is frequently present when members of the family are together and can actually observe their interactive behavior. She perhaps has the broadest contact with the mother and her human and physical environment.

The findings of this study indicate that some mothers needed assistance to interpret the meaning of their SIDS-sibling's behavior.

Nurses are in a position to provide some structured interventions to help mothers "step back" from the details of the SIDS-sibling's behavior and look, instead, at patterns and the variable meanings of those patterns. For example, through the use of anticipatory guidance about infant development or having mothers keep records of infants' sleep-activity patterns, nurses may provide information that will decrease maternal anxiety and offer alternative explanations for changes in infants' behavior. Discussions about the SIDS-sibling's behavior affords opportunities to clarify misinterpretations. As well, the nurse can validate parents perceptions about their infants, thus helping mothers to become more confident in their own parenting skills. As mothers discuss their SIDS-siblings with an active listener, it provides a means of confirming perceptions about the infants' adaptability. Such discussions may be particularly important when planning to discontinue the monitor.

Because doubts about parenting abilities may arise when mothers have experienced the unexpected death of an infant, opportunities to discuss ordinary baby care such as feeding or dressing for outside weather may be reassuring and promote the comfort of the mother in her role. Mothers who experienced the SIDS death of their first-born may be in particular need of opportunities to discuss infant behavior and care.

The greater-than-anticipated willingness of participants to discuss areas of their life that might be considered sensitive and painful, even months into the home monitoring experience, is a clue that nursing support should include frequent opportunities to discuss painful memories and present fears and anxieties. Results of this study indicated that mothers of SIDS-siblings were in more need of support during the following times:

1. When SIDS-siblings were ill.
2. During the early months when mothers know SIDS occurs more frequently.
3. Anniversary dates related to the previous infant.
4. When planning to discontinue the monitor.
5. During developmental changes, particularly involving sleeping and feeding patterns.
6. If the infant experiences apnea requiring intervention.

Comments from mothers indicate when events with the subsequent infant were similar to events that occurred prior to the SIDS death, mothers experienced more distress. For example, the mother who arrives in emergency with a SIDS-sibling who has developed a cold at exactly the same age as the previous infant prior to death, is understandably upset. In such a situation, the mother's concern is not just about an infant with a cold. Certainly, it suggests that questions need to be asked by health-care professionals to identify the psychological implications of mothers' concerns about SIDS-siblings, as well as SIDS-siblings' physical health an[illegible]ll-being.

Because of mothers' perceptions of avoidance responses by others toward SIDS-siblings, it might be important to touch or hold a SIDS-sibling frequently, during any nursing visit. Time spent with the total family, relatives and friends of the family may help to facilitate their understanding of the monitor and SIDS. Visits made when friends are present may also provide an opportunity for mothers to learn ways of explaining home monitoring and answering others' questions.

Some of the findings in this study indicate that mothers provided much instrumental care to SIDS-siblings but some were inclined to pay more attention to the technical aspects than the social nature of caregiving situations. Because SIDS-siblings are closely supervised and watched, mothers are in a favorable situation to enhance the infant's development through play and other social exchanges. Nurses should be aware of the importance of reminding mothers of opportunities for promoting the infant's development during the hours of close supervision.

Emphasis should also be placed on the value of time away from the infant and the value to the infant of contact with other adults, including the father. Ways of helping mothers to increase the number of people available for providing relief from infant care, would seem to be a priority for mothers in this group.

Mothers who had many problems related to life circumstances and were less energetic and involved with their infants may require a different set of nursing interventions. In these cases, maternal involvement with the SIDS-sibling may depend less on information about infant development and behavior and more on helping mothers to mobilize potential helpers who can provide physical and emotional support.

Because mothers used information about SIDS to help determine caregiving interventions, including times to worry about the SIDS-sibling, it may be important to ensure that mothers have accurate information about SIDS. For example, one mother in this study thought that the rate of SIDS for the second child increased from 1/1000 to 1/500.

Like all babies, the SIDS-sibling will outgrow the risk for SIDS. When parents perceive the infant is vulnerable, then hope for the child's survival may involve wishing away time that might rather be spent without the uncertainty and anxiety of a life-threatening event. Anxiety about the future can interfere with the ability to capture the enjoyment of an immediate moment. Feedback to parents about their infant's social behavior, developmental advances or responsiveness to the parent, can cue parents into those interpersonal moments to be enjoyed and reinforce their capabilities as parents. Nurses have a role in all health care settings with reference to promoting the parent's and infant's abilities to mutually enjoy time together and establish a relationship that will support the infant's health, growth and development.

Implications for Nursing Research

The results of this study have implications for further nursing research. Some areas to consider for research include:

1. The impact of a SIDS death on relatives and friends of the family.
2. The effect of social support, including nursing intervention, on the mother-SIDS sibling relationship.
3. The impact of home monitoring and loss of an infant due to SIDS on the father-SIDS sibling relationship.
4. The length and extent of grief reactions following the SIDS death and with the birth of the subsequent SIDS-sibling.

5. The long-term relative contributions of a SIDS death, home monitoring, life circumstances and social support on the parent-child relationship.
6. Stressful points during the home monitoring experience with a SIDS-sibling.

Because nursing contact with parents during the home monitoring experience is frequently done via the telephone, nursing intervention studies might include the effectiveness of various role cues and information given to mothers over the phone for promoting adaptive mother-infant relationships and influencing the ease of the home monitoring experience. This type of study may be particularly relevant for families in rural areas.

Recommendations

Prior to recommending specific changes in nursing-care of families with SIDS-siblings on the home monitoring intervention, a similar study should be conducted. The following recommendations are made to increase the generalizability and specificity of results:

1. A larger sample size.
2. The use of a control or comparison group such as a matched sample of mother-SIDS siblings not using the home monitoring intervention.
3. The refinement of questions to determine more specifically, the contribution of maternal perceptions of the SIDS-sibling on the mother-infant relationship.
4. The use of previously tested instruments to measure such variables as social support, life stress and the extent of grief reactions.

5. A longitudinal method to determine the stability and differences in the mother-SIDS sibling interaction in different contexts and during different points in the home monitoring experience.
6. The measurement of variables to determine more completely, the contribution of the SIDS-sibling to the ongoing mother-child relationship. These variables could include such measures as infant development, infant temperament and the predicatability of infant's sleep-activity patterns.

Mothers who were receiving ongoing care from public health nurses found this support very helpful. It is further recommended that a referral to public health nursing be made for mothers with SIDS-siblings on home monitoring. As well some mothers felt their initial experience with home monitoring may have been easier if they had received information about the apnea monitor during pregnancy rather than following the birth of the SIDS-sibling.

Because the infant and parent are a system, then a health concern related to the infant must affect both parent and infant and some aspects of the time they spend together. Based on the assumptions that: (a) parent-infant interaction evolves and changes with life circumstances and (b) the impact of stressful circumstances on the infant and parent will be reflected in the quality of their interaction, it is believed that any research on the impact of home monitoring should, in part, focus on the parent and child as an interactive system.

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APPENDIX 1

NURSING CHILD ASSESSMENT FEEDING SCALE (NCAFS)

Pages 148-152 inclusive have been removed due to the unavailability of copyright permission. The information on these pages included:

Barnard, K. (1978a). Nursing Child Assessment Feeding Scales. (Available from K. Barnard, University of Washington, Seattle Washington).

Caldwell, B. & Snyder, C. (1978). Home Observation for Measurement of the Environment Inventory (rev. ed.). (Available from B. Caldwell, University of Arkansas, Little Rock, Arkansas).

APPENDIX 3

GUIDELINES FOR DESCRIPTIVE DATA ABOUT SAMPLE

Information About HOME Monitoring

1. Date of previous infant's death ______________________________

2. Age of previous infant at death ______________________________

3. Birthdate of deceased infant ______________________________

4. Date home monitoring was begun with subsequent infant ______________________________

5. Dates of apnea or bradycardia episodes requiring stimulation or CPR to terminate

Nature and Date of Incident	Intervention

Information About Family

6. Marital Status: Single ____ Married ____
Widowed ____ Divorced ____

7. Date of birth: Mother ____________
Father ____________

8. Other children in the family:

Sex	Date of Birth
________	________________
________	________________
________	________________

9. Present Occupation:

Father: ____________________

Mother: ____________________

10. Years of Schooling:

Father: ____________

Mother: ____________

11. Highest academic level:	Mother	Father
Less than High School		
High School diploma		
Some College/University		
College/Univesity Graduate		

Information About SIDS Sibling

12. Date of Birth ____________________

13. Age of infant when home monitoring began __________

14. Weight of infant at birth ________________________

Premature: Yes ____ No ____

15. Infant is:

Breast fed ________

Bottle fed ________

On solid food ________

16. Do you have any concerns about your infant's feeding?

17. Do you have any concerns about your infant's growth or development?

18. Which category best describes your thoughts about the chance of your infant having an episode of apnea or bradycardia?

No chance ____________

[✓ Slight chance] ____________

Moderate chance ____________

Large chance ____________

19. Which category best describes how confident you are that the monitor feedback you receive is accurate?

1. Not confident in the accuracy of the monitor ________
2. Slightly confident in the accuracy of the monitor ________
3. Moderately confident in the accuracy of the monitor ________
4. Very confident in the accuracy of the monitor ________

20. How frequently (per day/week/month) do you communicate by phone or in person with:

	Frequency	Phone	In Person
a) a home monitoring buddy			
b) a community health nurse			
c) a staff member of the home monitoring program (nurse or doctor)			
d) a member of the SIDS group			

APPENDIX 4

INTERVIEW GUIDE FOR HOME INVENTORY

Interview Guide for Home Observation for Measurement of the Environment Inventory

The specific wording of these questions is based on the strategies and approaches recommended in the HOME Inventory Manual (Caldwell & Snyder, Note 5).

Initial Open-Ended Question

We are interested in knowing the kinds of things your baby does when he/she is at home. A good way to get a picture of what his/her days are like is to have you describe a typical day for your child--like yesterday, if that was typical. Just start from the time he/she wakes up and tell me all of the things he/she does, the things you do together and something about his/her routines.

Probing Questions for Specific Items*

Item 7--Messiness

Some children like to play with things that are messy such as mud, water or food. Does your child ever want to do this kind of activity? Do you have any special rules or guidelines for your baby and play that is messy?

Item 15--Discipline

What works best for you in terms of his or her discipline at this age? Do you ever need to physically punish him such as slapping his hands?

If Yes: About how often per week would you need to physically punish him/her?

Item 19--Pets

Do you have any pets in your home such as dog, cat, bird, fish, hamster?

---

* The order in which these questions are asked may vary to accommodate the flow of the conversation.

Item 20--Babysitters

A child as young as X often ties a mother down. Do you manage to have some time away in the daytime or evening?

If Yes: Who takes care of "X" when you are out? Can you usually count on him/her or do you have a different person each time?

Item 21--Grocery Store

Do you and X ever have the chance to go to the grocery store together?

If Yes: About how often would you be able to do this activity together?

Item 22-Outings

Do you ever have an opportunity for time outside of the house with x; for example, in the backyard, a walk, or visits to the neighbors?

If Yes: What kinds of activities do you do outside of the house? How often (per week or month) would you have an opportunity for these activities?

Item 23--Doctors Visits

How often does X visit the doctor or the community health unit?

Item 24--Place for Toys

Are there any special arrangements for where X keeps his toys?

Item 36--Household Chores

Getting household chores done can be difficult when you have small children who need a lot of attention. How do you arrange things while you are doing dishes, laundry or housecleaning? Is X usually asleep or on the monitor in another room or do you find yourself conversing with him/her while you are working around the house?

Item 37--Encourages Developmental Advance

What are some of the things that X is learning to do at this age? Have you been able to help him learn any of these new activities? What kinds of things do you do that help?

Item 38--Investment in "Maturing Toys"

Do you ever have a chance to sit down and play with X? What kinds of things do you do when you play together? How does X usually get started playing with a new toy he has never seen before? Can you help him get involved with the new toy or does he figure it out himsef?

Item 39--Structuring Play Periods

On a day-to-day basis, how does X get started playing with his toys? Do you sometimes find yourself sitting with him or does he get started on his own?

Item 40--Provides Challenging Toys

How do you usually decide what kinds of toys to select and offer X at his age? What are some of your guidelines?

Item 41--Care by Father

Is X's father able to do any of his care during the day or evening? What kind of care does he do and about how often?

Item 45--Number of Books

Does X have any books of his own? How many?

Item 42--Reading Stories

Does X sometimes like someone to read him a story? How often would this activity occur?

Item 43--Meal Arrangements

How do you manage meal times at your house? Do you feed X at the table with the rest of the family or does he usually eat his meals separately at another time?

Item 44--Relatives

How often do relatives come to visit your family?

Items 26-34--Toys

I'm interested in seeing some of your baby's toys, where he keeps them and some of his favorite things to play with.

If toys are not available for viewing:
What kinds of toys or items in the house does your baby like to play with?

and

I have a list of things to play with that some mothers have provided for their children. Which of these things does your baby have and can you add anything to my list?

(See Items 26-34, Appendix 2)

Item 11--Response to Praise

Find one or more occasions to praise some characteristic of the baby.

APPENDIX 5

RECORD OF MONITOR ALARMS

As part of the investigation about infants on home monitoring, I would like to know more about the number of monitor alarms that occur and your thoughts about the reason for these monitor alarms.

On the sheets attached to this form, please keep a daily record of each time a monitor alarm occurs, with the exception of the alarm that occurs when you are attaching your baby to the equipment.

On the sheets provided, there is a space to place:

1. The date of the alarm
2. The time of the alarm
3. Whether the alarm was continuous or intermittent
4. A check mark under the category which best describes your thoughts about the reason for the alarm.

Reason for Alarms

Apnea--check this category if the alarm occurred because the baby was not breathing adequately.

Bradycardia--Check this category if the alarm occurred because of the baby's heart rate.

Equipment--Check this category if the baby was okay and the alarm occurred because the equipment was not working properly or needed to be readjusted.

Uncertain--Check this category if it could not be determined whether the alarm occurred because of the baby's breathing and heart rate or the equipment.

Keep your record and I will pick it up during our last scheduled visit.

PARENTS' DAILY RECORDINGS OF MONITOR ALARMS

Place a check mark under the category which best describes your thoughts about the reason for the monitor alarm

Monitor Date	Alarm Time	Alarm Was		Apnea	Bradycardia	Equipment Wasn't Working Properly	Uncertain if Alarm was due to equipment or baby
		Continuous	Intermittent				

APPENDIX 6

CONSENT FORM

Informed Consent

SIDS Siblings on Home Monitoring: A Descriptive Study

Nurse Researcher: Sherry B. Hayward, R.N., B.Sc.N.
Master's Student
Department of Nursing
University of Alberta
Phone: 433-0152 (Edmonton)
249-9633 (Calgary)

I understand that I am being asked to participate in a nursing study to learn more about the experience of mothers and infants who are using the home monitoring intervention.

I am willing:

1. To discuss my infant's daily routines and schedules and how he/she is growing and developing.
2. To have the nurse researcher observe me in my home on two separate occasions while I feed my infant.
3. To provide some information on family background (e.g., dates of birth).
4. To keep a daily record for four weeks, of all monitor alarms and the reason the alarms occurred.

I understand there will be four home visits over a four week period including:

1. An interview to discuss family background information (30 minutes)
2. An interview with me and my infant to discuss my infant's daily routines and development (60 minutes)
3. Two visits to observe my infant while he is being fed (30-45 minutes each from the beginning to the end of the feeding)

I understand that:

1. I may refuse to answer any questions.
2. I may withdraw from the study at any time without penalty.
3. Information obtained by my participation will be strictly confidential.
4. The family members will remain anonymous in any reports or publications.
5. All identifying information will be destroyed following the completion of the written report.
6. There may not be any direct benefits to me or my family by participating in this study.
7. The nurse researcher will have access to my infant's hospital record.
8. A research assistant may also be present for some interviews and feeding observations.

I have been given the opportunity to ask questions about the study and they have been answered to my satisfaction. I understand that I can ask the nurse researcher further questions at the time of the home visits or by phone.

I voluntarily agree to participate as a subject with my infant in this study.

____________________ Date

____________________ Signature of Subject

I have discussed this study and the items listed above with the subject.

____________________ Date

____________________ Signature of Nurse Researcher